
Disability Rights and Independent Living Movement Oral History Project

The Computer Training Project in Berkeley, Accessible Technology, and Employment for People with Disabilities

Neil Jacobson:	Cofounder of the Computer Training Project; Cochair of the President's Committee on Employment of People with Disabilities
Scott Luebking:	Cofounder of the Computer Training Project; Advocate and Innovator in Disability and Computer Technology

Interviews conducted by
Sharon Bonney and
Mary Lou Breslin
in 1997, 1999, and 2000

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

Acknowledgements

The Disability Rights and Independent Living Movement Oral History Series was funded primarily by a three-year field-initiated research grant awarded in 2000 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, Dr. Henry Bruyn, June A. Cheit, Claire Louise Englander, and the Sol Waxman and Tina P. Waxman Family Foundation.

Series History

by Ann Lage

Disability Rights and Independent Living Movement Oral History Project

Historical Framework

The latter half of the twentieth century witnessed a revolutionary shift in the worldview and legal status of people with disabilities. In major cities across the United States, people with disabilities began in the 1960s and 1970s to assert their rights to autonomy and self-determination and to reject the prejudices and practices that kept them stigmatized, isolated, and often confined to institutions or inaccessible homes under the care of family members.

Within a few years of each other, groups of people—usually young, often with a university connection, and frequently wheelchair users with significant physical disabilities—formed organizations in Berkeley, New York, Boston, Denver, St. Louis, Houston and elsewhere to foster independent living in the community and to advocate for laws and policies to remove barriers to autonomy. Characterizing these groups, which formed relatively independently of each other, was the evolution of a new core set of beliefs that gave a distinctive character to this emerging disability rights and independent living movement. Their members came to insist on self-determination and control over their organizations. They resolved to make changes in their own lives and in society. And as they engaged in political actions, they began to recognize the shared experience of discrimination and oppression among groups with diverse disabilities.

Very quickly, informal regional and national networks of activists developed, often including people with a range of disabilities, who shared information about the nuts and bolts of funding, peer counseling, and service delivery. They joined together to advocate for essential personal assistance services and for the removal of architectural and transportation barriers. These networks were formalized in national organizations, such as the American Coalition of Citizens with Disabilities (founded in 1975), and national gatherings, such as the 1977 White House Conference on Handicapped Individuals, which served in turn as catalysts for national and grassroots organizing on a cross-disability basis.

From the beginning, the movement was a part of the activist and countercultural climate of the times, evolving within the context of civil rights demonstrations, antiwar protests, and the emerging women's and gay rights movements. Early leaders such as Judith Heumann, Fred Fay, Ed Roberts, Lex Frieden, and a host of others conceptualized their issues as a political movement, a struggle for the civil rights of people with disabilities. A wide-ranging group of activists absorbed this civil rights consciousness and cross-disability awareness during a series of defining political actions, such as the nationwide sit-ins and demonstrations in 1977, organized to demand the issuance of regulations for section 504 of the Rehabilitation Act, and during the subsequent peer trainings on the rights of people with disabilities, which were carried out nationwide.

As the political movement grew, the new cadre of activists made connections with the emerging parents' movement and its efforts to free people with developmental disabilities from the massive and dehumanizing state institutions of the time. A series of landmark federal lawsuits, most notably *PARC v. Pennsylvania* (1972) and *Mills v. Board of Education* (1972), established for the first time a right to a public school education for children with disabilities. Alliances and coalitions also developed with a number of traditional, disability-specific organizations, which were themselves undergoing changes during this period.

New organizations devoted to pursuing legal and legislative reforms, such as the Disability Rights Education and Defense Fund (1979), ADAPT, a grassroots direct-action organization (1983), and a growing number of other local, state, and national disability organizations and alliances, profoundly influenced national policy in education, transportation, employment, and social services. Their best known legislative victory was the passage of the Americans with Disabilities Act in 1990, which, although compromised by subsequent court decisions, offered broad civil rights protection for disabled Americans and has served as a beacon for the creation of disability rights legislation in fifty other countries.

Less concrete than the legislative accomplishments and legal cases, and still evolving, is the shift in attitudes and consciousness that was driven by, and has transformed the lives of, people with a wide variety of physical and mental disabilities, challenging the notion of disability as stigma and instead embracing disability as a normal facet of human diversity. Theoreticians and artists with disabilities play a prominent role in defining and communicating concepts of disability community and disability culture, and academicians are promoting disability as a category of cultural and historical analysis.

These achievements, as significant as they are, have not ended the discrimination or the prejudice. Indeed, the first years of the twenty-first century have seen several Supreme Court decisions which have limited the expected scope and effectiveness of disability rights law, and many disabled Americans remain economically and socially marginalized. While the need for change continues, the tremendous accomplishments of the disability rights and independent living movement cannot be denied. American society has been profoundly transformed, and any accurate account of the social and political landscape of the late twentieth century will acknowledge the contributions of disability rights and independent living activists.

Project Design, Interviewees

The Disability Rights and Independent Living Movement Project at the Regional Oral History Office, the Bancroft Library, UC Berkeley, preserves, through oral history interviews, the firsthand accounts of the activists who have made significant contributions to the origins and achievements of this movement. The Bancroft Library also collects, preserves, and provides access to the papers of organizations and individuals who have been a part of the struggles for disability rights and independent living. All of the oral history texts, finding aids to the archival records, and selections from the archival papers and images are available on the Internet, as part of the Online Archive of California, California Digital Library.

The first phase of the project, completed in 2000, documented the movement during its formative years in Berkeley, California. Berkeley was the site where the concept of independent living was most clearly articulated and institutional models developed, originally by and for students on the Berkeley campus and soon after in the community, with the founding of the nation's first independent living center in 1972. These organizations and their dynamic leaders, together with the activist tradition in the Bay Area and a disability-friendly climate, made Berkeley an important center of the disability movement and a natural focus for Phase I of the project.

During Phase I, Regional Oral History Office interviewers recorded forty-six oral histories with Berkeley leaders, many of whom have also been figures on the national scene. The Bancroft Library collected personal papers of interviewees and others in the disability community and archival records of key disability organizations, such as the Center for Independent Living, the World Institute on Disability, the Disability Rights Education and Defense Fund and the Center for Accessible Technology.

Phase II of the Disability Rights and Independent Living Movement Project (2000-2004) expanded the oral history research and the collection of archival material to document the growth of the movement nationwide. The project again focused on those leaders whose activism began in the 1960s and 1970s. The forty-seven Phase II interviewees include founders and organizers of disability rights groups and early independent living centers in New York, Boston, Chicago, Texas, and California. Of these, many have also been national leaders in the movement and founders of national organizations. Many in this group, like the Berkeley interviewees, were among those who helped to conceptualize disability rights as a political movement and shaped the programs and philosophy of independent living. Others have been key figures in the development of disability rights law and policy, as organizers, strategists, and lobbyists behind the scenes.

A number of interviewees have held positions in state and federal government agencies and commissions, helping formulate government law and policy on transportation access, social security and health benefits, and personal assistance, education, and rehabilitation services. Several have worked to free disabled people from institutions, and others reflect on their own experiences living in institutions. Some interviewees were deeply involved with the parents' movement.

The international disability movement is represented by Yoshihiko Kawauchi, a leading proponent of universal design and disability rights in Japan; many American activists interviewed for the project also have connections to the international movement. Two interviewees are pioneering artists with disabilities, who discuss their careers as artists and the relationship of art and advocacy. Several have taught disability studies at colleges and universities, contributing to the concept of disability as a category of analysis analogous in many ways to class, race, gender, and sexual orientation.

A series list of project interviews follows the transcripts in each printed volume. The project Web site (http://bancroft.berkeley.edu/collections/drilm/) offers the researcher four points of access to the collection: by geographic location, by organizational affiliation, by research themes addressed, and by name of interviewees. There is no claim to completeness in the collection; further interviews are planned pending additional funding for the project.

Interview Themes and Topics

An overarching research goal for both phases of the Disability Rights and Independent Living Movement Project was to explore and document how a broad group of people with disabilities, in key cities across the country, initiated and built this social movement, and how it evolved nationally, within the context of the social and political fabric of the times. Lines of inquiry include social/economic/political backgrounds of interviewees and family attitudes toward disability; experiences with medical and rehabilitation professionals and with educational systems; identity issues and personal life experiences; involvement in civil rights or other social movements of the era; and developing consciousness of disability as a civil rights issue.

Interviews record how people with disabilities built effective organizations, with information about leadership, organizational structure and style, organizational turning points, stumbling blocks, achievements, and failures. Challenges particular to the disability community are addressed; for example, leaders of independent living centers point out the difficulties of providing much-needed services to clients and answering to government funding agencies for their service mandate, while still maintaining the essential advocacy roots of the independent living movement.

Interviews explore the building of national alliances and coalitions, investigating networking among groups from different locales and among groups accustomed to aligning on the basis of a single disability. Indeed, the issue of inclusiveness within the movement—the nature and meaning, and sometimes tenuousness, of cross-disability alliances and the inclusion of newly recognized disabilities—is a complex and significant theme in many project interviews, and offers an area for future oral history research.

Interviews document the range of efforts—from protest demonstrations, to legislative lobbying, to litigation in state and federal courts—to influence disability law and policy, to embed disability rights into the canon of civil rights, and to alter and expand the very definition of disability. Several interviews also reflect on a recent philosophical shift of some movement thinkers, who draw on a human rights framework and acknowledge the disability community's need for social supports along with equality of opportunity and civil rights.

Also examined by many narrators are race, gender, and sexual identity issues: the role of women (large) and minorities (limited) in the movement; the development of programs for women and girls with disabilities; questions of sexuality and disability; and the disability movement's relationship over the years with the women's, gay and lesbian, and African-American civil rights movements. The involvement of able-bodied advocates, including parents of children with disabilities, is examined by many interviewees, both disabled and able-bodied, with telling accounts of often awkward and sometimes painful struggle over their place in the movement. (For instance, one organization toyed with the idea of granting able-bodied members only three-fifths of a vote.)

Another important theme running through these interviews is the question of equal access. This includes the impact of technological advances—from motorized wheelchairs in the early days of the movement to adaptive computer technologies more recently, all of which have profoundly extended opportunities for people with disabilities. And it includes the campaigns, legislation, and lobbying—on campuses, in communities, and in Congress—for removal of architectural barriers to people with disabilities, for access to public transportation, and for access to personal assistance services, all essential requirements for independent living.

Many interviewees reflect on the process of developing a disability identity and a sense of belonging to a disability community. Several explore the concept of disability culture and its expression in the arts and in media, and theoretical explorations of disability by scholars and educators. Interviewees who have pioneered the fields of disability scholarship, arts, and ethics point out the contributions of disability studies to the broader society in fostering new and more complex ways of thinking about the body, about normality, about crucial ethical issues relating to abortion, euthanasia, and physician-assisted suicide; and in contributing a unique disability perspective to scholarship in history, literature, and cultural studies.

Project Staff and Advisors

Since its inception the project has been collaborative, with staff members and advisors drawn from the disability community, from academia, and from the Bancroft Library and its Regional Oral History Office. The national advisory board for Phase II includes disability rights leaders Fred Fay, from Boston, and Lex Frieden, from Houston; scholars Frederick Collignon and Sue Schweik from UC Berkeley, Paul Longmore, historian from San Francisco State University, and Karen Hirsch, disability scholar from St. Louis.

Ann Lage directed the project for the Regional Oral History Office, providing years of experience in oral history and leadership for the interviewing team. Interviewers for the project had a unique set of qualifications, combining historical perspective, training and experience in oral history methods, personal experience with disability, and, frequently, activism and participation in disability organizations. Oral history interviews were conducted by 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, cofounder and former president of the Disability Rights Education and Defense Fund, policy consultant and lecturer on disability civil rights topics, and Henry Betts Award winner; Kathy Cowan, librarian for a public interest law firm; Esther Ehrlich, oral history interviewer and editor in the areas of disability arts and community history (who also took on myriad project management responsibilities); and Denise Sherer Jacobson, writer and educator on disability issues *(The Question of David, A Disabled Mother's Journey through Adoption, Family, and Life*, 1999). David Landes, former coordinator of student affairs for the Computer Technologies Program in Berkeley, took a less active role in Phase II when he was appointed to a full-time faculty position in economics. Susan O'Hara, former director of the Disabled Students' Program at UC Berkeley and the initiator of the original idea for this project, again served as consulting historian, occasional interviewer, and convenor of monthly project meetings.

Conducting interviews in Massachusetts and Washington DC was Fred Pelka, a writer specializing in disability rights politics and history, author of *The ABC-CLIO Companion to the Disability Rights Movement*, and a recipient of a 2004 Guggenheim Fellowship for his proposed book, "An Oral History of the Disability Rights Movement." Harilyn Rousso, educator and consultant on issues of women and girls with disabilities, moved from project interviewee to interviewer, conducting one New York oral history and then organizing and moderating a videotaped group discussion with four New York advocates. The Regional Oral History Office production staff, coordinated by Megan Andres, transcribed interviews and carried out other production tasks.

Bancroft Library project personnel in the Technical Services unit collected, arranged, and catalogued personal papers and organizational records and prepared detailed finding aids. They included Jane Rosario, supervising archivist, and project archivists Susan Storch and Lori Hines, all under the supervision of David DeLorenzo, head of Bancroft Technical Services. The staff of the Berkeley Library's Digital Publishing Group, headed by Lynne Grigsby-Standfill, prepared the oral histories and other texts, photographs, and finding aids for digital archiving in the Online Archive of California. Brooke Dykman designed the Disability Rights and Independent Living Movement Web site. Theresa Salazar as curator of the Bancroft Collection, provided curatorial oversight for the project.

Oral History and the Oral History Process

Oral history provides unique and irreplaceable sources for historical study. It preserves the reflections and perspectives of those who have participated in historical events, documenting with firsthand accounts how events happened, how decisions were made, and the behind-the-scenes interplay that underlies the public face of an organization or social movement. Beyond documenting what happened and how, the words of participants reveal the personal and social contexts and the institutional and political constraints which profoundly shape events but may not be apparent in the written record. Most significantly for this project, oral histories offer an opportunity to elicit reflections on often elusive matters of identity, changes in perception and consciousness, and the personal experience of living with a disability. Finally, they provide a record of how people remember and understand their past, often a indication of personal values and cultural meanings.

The DRILM project team, primarily based in Berkeley, all contributed to the original design of the project and assisted in developing interview protocols. Bay Area interviewers were joined by Fred Pelka from Massachusetts for a two-day orientation session in December 2000 and by telephone during regular monthly meetings, held to plan and evaluate interviews and review progress. Interviewers assigned to document the movement in a particular location conducted research to choose potential interviewees and interview topics. Once narrators were selected and arrangements made, they prepared a preliminary outline before each interview session, based on interview protocols, background research in relevant papers, consultation with the interviewee's colleagues, and mutual planning with the interviewee. The length of each oral history varied according to the length and complexity of the narrator's involvement in the movement, but also was dictated by scheduling and availability limitations.

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 to give additional information when needed, but to preserve the transcript as much as possible as a faithful record of the interview session. The final stage added subject headings, a table of contents, and an index (for the print versions). Shorter transcripts were bound with related interviews into volumes; longer transcripts constitute individual memoirs. Interviewees were offered the opportunity to seal sensitive portions of their transcripts, or omit them from the Internet versions.

There are nearly one hundred oral histories in the Disability Rights and Independent Living Movement series. Nearly all of them are available via the Internet in the Online Archive of California (http://www.oac.cdlib.org/texts/); they also can be accessed through the project Web site at http://bancroft.berkeley.edu/collections/drilm/

Print 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 organizations and individuals for cost of printing and binding. Many of the oral histories are supplemented by a videotaped interview session. Video and audiotapes are available at the Bancroft Library.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. The office is under the direction of Richard

Cándida Smith 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://bancroft.berkeley.edu/ROHO/.

The Bancroft Library's Disability Rights and Independent Living Movement Project, of which these oral histories are a part, was funded by field-initiated research grants in 1996 and 2000 from the National Institute on Disability and Rehabilitation Research [NIDRR], Office of Special Education and Rehabilitative Services, U.S. Department of Education. 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 effort over the years: Dr. Henry Bruyn, June A. Cheit, Claire Louise Englander, Raymond Lifchez, Judith Stronach, the Prytanean Society, and the Sol Waxman and Tina P. Waxman Family Foundation.

Ann Lage, Project Director
Regional Oral History Office
The Bancroft Library
University of California
Berkeley
April 2004

Disability Rights and Independent Living Movement Oral History Project

Neil Jacobson

Cofounder of the Computer Training Project; Cochair of the President's Committee on Employment of People with Disabilities

Interviews conducted by
Sharon Bonney
in 1997

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

Foreword

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

Copyright and Use Restrictions

Citation

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

> Neil Jacobson, “Cofounder of the Computer Training Project; Cochair of the President's Committee on Employment of People with Disabilities” an oral history conducted by Sharon Bonney in 1997, in *The Computer Training Project in Berkeley, Accessible Technology, and Employment for People with Disabilities*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2004.

Tape Guide

Interview History—Neil Jacobson

Neil Jacobson is important to the history of the independent living movement because of his history and background as a person born with a disability, his involvement as a youth with the disabled community on the East Coast, his role in developing the Computer Training Project through the Center for Independent Living, and his adult work in the corporate world.

Neil's involvement with the disability community began when he was four and a half years old and continues to this day. Even at that early age, he recognized that kids with disabilities were segregated and that segregation was a common enemy, and that his segregated school class had power. He participated in some of the earliest disabled rights activities on the East Coast with Judy Heumann and others who eventually found their way to Berkeley.

Disabled at birth, Neil's formative years reflect parental fears, influenced by the Holocaust, for his safety as a disabled child; grinding daily therapy routines; negative interactions with rehabilitation professionals; and an awakening to the possibilities of the future. His perspectives and insights on growing up with a disability are illuminating.

After graduating from Hofstra University, Neil moved to Berkeley for graduate work in computer science in 1974. He was immediately hired by Ed Roberts at the Center for Independent Living. The philosophy of independent living was applied to the establishment of the Computer Training Project, started with funding from IBM. Students were not only taught computer programming but independent living skills as well.

Rather than remain in the disability field, Neil joined the corporate world and is now a senior vice president of Wells Fargo Bank in San Francisco.

Four interviews were conducted in Neil's dining room and in a detached office behind his home. The atmosphere was casual, with the family cat sitting in the interviewer's lap in one session and Neil's son, David, age ten, offering side comments to his father's comments in the first interview. Mr. Jacobson frequently laughs or chuckles while he speaks, and the interviews reflect his personality in this way. Because of his speech involvement from cerebral palsy, the interviewer needed clarification, at times, of what Neil said, and these are reflected on tape and in the transcript. The transcript was lightly edited by Neil and the interviewer.

After the oral history was completed, an interview was videotaped with Mr. Jacobson in his home. Both the video and audio tapes are available for viewing and listening in the Bancroft Library.

Sharon Bonney
Interviewer/Editor
September 2000
Emeryville, California

I. Family Background, Early Connections to Disabled Community, and Life in Berkeley, 1952-1974

Parents' background and effects of Holocaust

[Interview 1: March 4, 1997] [Tape 1, Side A]
[1]

Bonney: Neil, tell me when you were born and where you were born.

Jacobson: I was born on December 19, 1952, in Brooklyn, New York.

Bonney: Tell me about your parents. Where were they born? What are their names?

Jacobson: My parents [Guta and Jack Jacobson] are survivors of the Holocaust. They were born in Poland in a city called Lodz and they came to the U.S. in 1949.

Bonney: Were they interned in concentration camps?

Jacobson: Yes. My mother was in Auschwitz for about five months. My father never made it to a camp when he was in the ghetto. My father was a trolley car driver and he drove people from the ghetto to the railroad to go to the camp. Now, in 1945 when there were only about a hundred people left in the ghetto, they told everybody to dig their own grave and my father dug his own grave. That night they were liberated by the Russians. That's how he escaped.

Bonney: I didn't quite get—they were ordered to dig their own graves and he dug his own grave.

Jacobson: They were all to be killed in the morning. That night the Russians came and they were liberated.

Bonney: I would imagine that this experience shadowed your entire life. Has it affected your family and you?

Jacobson: Yes. There's no doubt in my mind that I am who I am because of the Holocaust. There was both good and bad. The bad part is that because of the Holocaust my parents were always scared it might happen again, scared because of my disability because during the war people who were disabled were always, always killed. The bad part is that my parents were always very scared. The good part is that they are survivors and that they do have a survivor's mentality and I think they gave that to me. They believed that the world is worth surviving for. They believe that the world is worth fighting for. I really believe that they gave that to me and my brother [Steven Jacobson] and my sister [Eta Jacobson Wright]. I really believe that the world is okay.

Bonney: You said that your parents were always afraid because you were a disabled child. Do you mean here in the United States? What did they think might happen? Are there instances you can tell me about?

Jacobson: It was very hard for them to accept the fact that I was disabled. They never wanted me to have a wheelchair. To them the whole goal was to walk. If I could walk, I would be okay. They would work very, very hard to see that I could walk. For hours every day, day in and day out, they would give me therapy, take me to therapy, take me to doctors. The whole goal was to walk.

---

1. A guide to the tapes follows the table of contents.

Bonney: I didn't catch the two things you said—day in and day out they gave you therapy?

Jacobson: Hours and hours of therapy at home.

Bonney: Oh, at home.

Jacobson: I never had a wheelchair until I was in high school. Did you get that?

Bonney: Yes, I'll let you know when I don't understand.

Jacobson: When I did get a wheelchair for high school, my father built a dog house for the wheelchair.

Bonney: A dog house?

Jacobson: Yes, because he didn't want the wheelchair in the house. To him, the wheelchair was a symbol of disability. A symbol of pity.

Bonney: Let me ask you a question back a little bit. Did your parents know each other during the Holocaust or did they meet afterwards?

Jacobson: They got together after the war. After the war, my father went to live with his brother and my mother went to live with her sister. They happened to be married and that is how my mother and father got together.

Bonney: Okay, now let's go back to your childhood. Since you didn't get a wheelchair until you were in high school, how did you get around as a child until that time? Did you walk?

Jacobson: [chuckles] Did I walk? I hobbled. I hobbled. I don't know if you call it walking. I did walk a little with Canadian Loftrands [crutches], which I called 'canes'. I spent more time on the floor than I did on my feet. My father used to carry me a lot by his hands under my armpits. I did get around on my hands and knees and then when I was about ten years old, I used a bike and I got around on the bike.

Bonney: How did you get around in school?

Jacobson: [chuckles] Sometimes I got to push a chair by standing behind the chair and pushing it. Sometimes I used my canes. Sometimes I'd take the chair. When I went to high school and college I had a manual wheelchair. I used to get around by kicking backwards.

Bonney: I would imagine from what you told me that your home was not accessible.

Jacobson: Yes.

Bonney: Can you describe your house?

Jacobson: Growing up I lived in two homes. Before I was five years old, I used to live on the second floor of a walk-up. I don't remember that too well. Then after five, I lived in a house that had about five steps and I do remember that house. I used to get around on my hands and knees.

Bonney: You said you got therapy every day for hours trying to make you walk. Were you ever sent to a school for kids with disabilities or were you always in an integrated school setting?

Jacobson: Before we go on about school, I want to describe a little bit about my home therapy because I think it is interesting. Right after breakfast, my mom used to clear the dining room table, put a blanket on the table and put me on the table. For about forty-five minutes my mom would stretch, stretch every muscle in my body. Then after forty-five minutes my mom used to take me off the table and put me against the wall and make me stand and walk without holding on. I remember one day I made about five steps and I think that was one of the happiest days for my mom. Let me tell you what happened right before school. When I was four years old, the doctor figured that it would be better to put me into an institution. My father visited the institution and my father got scared out of his mind. My father saw kids laying on the ground, hungry, and naked.

Bonney: Hungry and naked?

Jacobson: Yes. And my father really got scared. Now don't forget, they were both immigrants and they didn't know that they could say no to the doctor.

So my mom ran away with all three kids and we went away from New York for about half a year. My father stayed in New York and my father told the doctor that the reason my mom left was that she got scared that they were going to take me away. When we came back to New York, the doctor decided not to talk about putting me away any more. But instead, to put me into a public school—a public, segregated school.

Bonney: Let me ask you a follow-up to your mother taking you away. Before the Holocaust started, Jewish people and people with disabilities in Europe—Poland, Germany and wherever—were put into institutions. The children were taken away from the family, told they were going to be given tests, and they never saw them again. They did murder the children. Were your parents afraid—was that their basis for their fear?

Jacobson: That's part of it and the other part of it is that my father saw with his own eyes what was going on in that institution. That really scared the hell out of him.

Bonney: You can understand that. Neil, how did it make you feel—your parents insisting that you walk, that you go through grueling therapy sessions every day, life being really hard getting around, house not accessible. Did you think about that as a child and, if so, what did you think about it?

Jacobson: Okay. Believe it or not, my father really helped a lot. My father always told me, "Neil, you are very ugly. You are very hard to look at. I am sorry you are disabled. It is hard for me to cope with your disability, but you are who you are. You always have to make the best of it." To me that was a very powerful statement. The idea that yes, you are not normal; yes, you are not easy to look at; yes, it is a horrible thing but that is the way it is. I found that to be a very positive statement. Do you follow me?

Bonney: Yes.

Jacobson: It is interesting, even though my mom was much more supportive, I think I got more from my father. My mother always made a big deal about how smart I was and told me that because of my intelligence I could do anything. That was a very positive statement and I do appreciate it a lot. But there was something about my father's honesty, raw honesty, that I really think I got a lot from it.

Bonney: You got your grit from him.

Jacobson: Yes.

Bonney: Do you think that's what helped make you strong and to feel like the world is okay and you wanted to be in it?

Jacobson: Exactly. It's like from the beginning I knew that the world was not the way I wanted it to be. The world is not always a bed of roses; that the world is hard and the world is tough, but it's okay because that is the way it is. I always found that raw honesty to be uplifting.

Judy Heumann's organizing in elementary school

Bonney: Uplifting to you. Okay, let's talk about your school days. Hold on one second. [tape interruption] You said that when you went to school, was it kindergarten that you first went into?

Jacobson: Yes.

Bonney: That you were put in a public but segregated school. What was that?

Jacobson: First of all I've got to tell you I feel lucky all my life. I've lived a very wonderful and lucky life. I went to kindergarten with a group of wonderful, powerful, excited disabled kids like Judy Heumann. When I was in kindergarten, Judy was in my class together with Michael Ward and Steve Hofmann. Do you know Steve? He is a local guy now. Michael Ward works for the Department of Education now. He has a PhD in education. You know Judy?

Bonney: Of course. Yes.

Jacobson: I've got to tell you that when I was four and a half, Judy was nine and she was already a political dynamo.

Bonney: A political—

Jacobson: Dynamo.

Bonney: [laughter] At nine years old!

Jacobson: Yes. Judy was already talking about the disabled movement—about how we've got to get out of these segregated classrooms and it was wonderful. It really was.

Bonney: At nine years old, did she act on her beliefs?

Jacobson: Yes. She was always organizing us kids. Don't forget I was four and a half so I don't remember details. I do remember her being very verbal and very political even at that time. One more thing I've got to tell you.

[Tape 1, Side B]

Jacobson: One more thing I got to tell you. When I was four and a half years old, I couldn't eat by myself, and Michael Ward needed help eating and so did Steve Hofmann. Judy Heumann, at nine years old, fed us all lunch.

Bonney: At the same time?

Jacobson: Yes, and I don't know if Judy will appreciate this but that is a real skill—not to go too quick, not to go too slow, not to go too far in. It is a real trip. She was one of the best feeders I ever had. [laughter]

Bonney: Well, I'm sure when she gets her interview we'll be asking her about that—where she learned to do that.

Jacobson: She still has that skill.

Bonney: Does she still feed you?

Jacobson: Yes. The point is, and this is very important, we all hated being segregated, but you know what, looking back I really believe that the power I have today came in a big way from being with other disabled kids. Hey, we were all disabled, we were all equal and we all had a common goal. A common enemy if you will.

— 14 —

Bonney: And that enemy was—

Jacobson: To get away from segregation. But that enemy, I think gave us power. We learned how to organize, we learned how to fight for what we wanted. I don't know what kids do today, but I really feel that we got a lot from each other.

Bonney: Neil, there is a story going around that when you were young and I am assuming in this school, but it might have been a different school, that you were in a class with developmentally disabled children and that you did their homework for them. Can you tell me about that?

Jacobson: Being in a segregated class there were only about fifteen of us in the class. Yes, some of us were smart and some of us were more disabled than others and some of us had developmental disabilities. Like I said before, I really felt that we got power from that. Yes, I did. I did do their homework, but they helped me in other ways.

Bonney: What other ways?

Jacobson: They would feed me. My memory is a very happy class. A very happy group of kids. I excelled in academic areas. But I felt that we all excelled in our own way.

Bonney: Did you get in trouble for doing their homework. Was it an issue?

Jacobson: Yes.

Bonney: Did you care?

Jacobson: No. Like I said we were a bunch of rowdy kids. Can you imagine Judy Heumann, at nine, she was a very rowdy kid and I think that is great.

First integrated school setting

Bonney: What else happened to you during your school years? How was high school?

Jacobson: High school was phenomenal. I had a marvelous, marvelous high school. High school was the first time that I was in a non-segregated class.

Bonney: The first time you were in a non-segregated class?

Jacobson: Yeah. I found out very quickly that I was just as smart as my non-disabled peers, and I was in all the honor classes. It was wonderful. I even began working in high school. In high school I got a job as a volunteer in the library. I began in the tenth grade and I did that for three years. Like I said it was wonderful. In the library, I met my first girlfriend. You know I still remember her. I don't know where the hell she is—but I can remember.

— 15 —

All during high school, I stayed at the school and I became a member of a couple of clubs.

Bonney: Now you said that you stayed at the school. You lived there?

Jacobson: No.

Bonney: What do you mean you stayed there?

Jacobson: We were supposed to go home on the bus at three o'clock, but the clubs were all after-school clubs, and I finally convinced my mom to allow me to stay. And I think that staying after school is very important. I was in a chess club.

Bonney: A chess club?

Jacobson: Yes. I was also in a computer club. I think that was one of the most wonderful, wonderful times. My home was about ten blocks away from the high school and I had a couple of friends who would push me home. Then I decided that I could kick home and I would kick. I remember I lied to my family a couple of times and I told them that I could get a ride home when in reality, I kicked. You know, I've got to—

Bonney: A little rebellion is good now and then.

Jacobson: And I really think that to be independent is so important.

Bonney: Now when you were in high school, was this the first time that you were with non-disabled kids? You were in a segregated classroom your whole elementary years?

Jacobson: Yes.

Bonney: So you were kept separate all that time?

Jacobson: And be aware that in high school, I don't know if they do this now, but they did something that I really appreciated back then. Do you know what a homeroom is?

Bonney: Of course.

Jacobson: Well, we had a segregated homeroom and I remember that I really liked that. I really liked knowing that I had a home base where my peers were. I got a lot of positive feedback from my home room. Then I went out to the normal classes. That was a really nice model, and I don't know if that is still going on. That was a great model.

Bonney: Let's go back to a different aspect of your childhood for a couple of minutes. You have siblings, right?

Jacobson: Yes. I have one sister and I have one brother. My sister lives in New York now and my brother is in Washington. My brother works as a virologist and is a good guy.

Bonney: He is a what?

Jacobson: A virologist.

Death of brother at birth

Jacobson: You probably don't know about my other brother.

Bonney: I'd love to hear about your other brother.

Jacobson: My sister was born in Germany before my parents came to the U.S. My parents came to the U.S. in 1949. In 1950 my mom gave birth to a boy and the boy was born with the umbilical cord around his neck and he couldn't breath. The doctor told my father that they recommend that the boy be allowed to die and he did. In 1952, I was born with the umbilical cord around my neck. [laughter] But I did not die!

Bonney: And we're glad of it!

Jacobson: I think about that a lot.

Bonney: Why didn't you die? What were the circumstances that were different?

Jacobson: Okay, a couple of things besides luck [chuckles] and luck has a lot to do with it. Before I was born my mother asked the doctor for a Cesarean because my mom, and her mom, had problems giving birth to boys. My mom had problems a couple of years before. The doctor said to my mom, "What do you know, you're only an immigrant?"

Bonney: So—

Jacobson: When I was born I think he felt obligated to put me in an incubator and I did survive. Four years later, my mother did have a Cesarean and they found that my brother also had the umbilical cord around his neck.

Bonney: She was really right—she had trouble giving birth to boys.

Jacobson: Yes. I think it was a phenomenon of being in the womb for nine months and having nothing to do but play with the umbilical cord. Like I said, I think about that a lot. I do. I do. I believe there is a reason I am here and the fact that I have a disability is the way it was meant to be.

Bonney: Do you blame the doctor at all?

Jacobson: No.

Bonney: For your brother's death or for your disability?

Jacobson: No. No. Like I said, I really believe that it happened because that was supposed to happen. To blame people—I don't know why the hell we have to do that. I think that is a waste of time. I think it's just great to know that we are here.

Saturday recreation program

Bonney: One other question about high school. When you were in the segregated school setting, was Judy Heumann in that school also?

Jacobson: No. No. When I was in the second grade they opened another segregated school closer to my home and Judy and I separated. We continued to be friends but not in school. Be aware that in New York they had a recreation program on Saturday for disabled kids. That's where I met my wife, Denise.

Bonney: Oh, as a child you knew each other. Boy, you get around, Neil!

Jacobson: New York is wonderful. No matter how big New York is, because they had all these segregated programs, you really get to know your peers. You have to hear this. The recreation program on Saturday was not a lot of fun. It wasn't.

Bonney: It wasn't a lot of fun?

Jacobson: No. But, again, I'm happy I did that. Again, there is something about having this common bond, having this common enemy. I do think I learned a lot. Do you follow me?

Bonney: So, it seems to me that most of your early childhood on you were really connected with the disability community—

Jacobson: Exactly.

Bonney: A lot more than many of us.

Jacobson: Exactly, that is my whole point. I grew up with the disabled movement mentality even though there was no disabled movement. We all knew we were disabled. We all knew we had a common bond. We all knew we had a common enemy. We all knew what the goal was. The goal was to get over that. The goal was to do away with segregation. That is very powerful.

A horrible summer at Haverstraw Rehab, 1965

Bonney: When we first started the interview, you asked if you could—did I jump? Is there something more that you wanted to say?

Jacobson: Because we all talk about the way we grew up, I think we have to talk about the rehab center.

Bonney: Oh, I didn't know about the rehab center. Go ahead.

Jacobson: When I was twelve years old, for the summer, all the other kids went to a camp and I went into a rehab center to learn how to walk. [laughter] I was there for ten weeks and it was the worst ten weeks I have ever, ever spent. The good thing is I know what the worst is. It was horrible.

Bonney: Do you want to tell me the name of the rehab institute?

Jacobson: Haverstraw. Have you been there?

Bonney: I've heard of it.

Jacobson: I remember that it was right next to a graveyard. I often wondered how many people graduated from Haverstraw to the graveyard. I was sent there to learn how to walk. Believe it or not, I didn't learn how to walk.

Bonney: [laughs] What a surprise!

Jacobson: But I learned a lot about discrimination and about hierarchy in the rehab center. There was a very clear hierarchy—people with cerebral palsy were on the bottom and people who were on top were paras.

Bonney: Who were—people who were better?

Jacobson: On top. P-a-r-a-s.

Bonney: Oh, paras [paraplegics]. I'm sorry. Paras were better than people with cerebral palsy?

Jacobson: Oh yes. A couple times I was going to the bathroom and I would be kicked off the pot by a para. And I would stay on the floor until they would come in and pick me up.

Bonney: The paras did this to you—the other disabled kids in the program?

Jacobson: And I had to go to counseling. Every disabled person needs counseling. [laughter]

Bonney: Hold that thought, Neil.

[Tape 2, Side A]

Jacobson: I had to go to counseling because every disabled kid needs counseling. Before I went to rehab I was a happy kid. I wanted to be a lawyer. The counselor said no way, forget it. How can you be a lawyer? You can't talk clearly. Okay? He recommended that I become a computer programmer.

Bonney: Why did you take his advice?

Jacobson: Because he was a doctor.

Bonney: Is that why you became a computer person?

Jacobson: You bet. Can you believe that?

Bonney: I'm not sure I do. Really?

Jacobson: Yes.

Bonney: That shows the power that these people have over children—young adults.

Jacobson: Believe it or not, that wasn't even the worst part. Before I went there, I was close to my brother. I was close to my sister and I had friends that I counted on who were part of my life.

Bonney: You had friends who—?

Jacobson: I had friends who lived in the area where I lived.

Bonney: Okay.

Jacobson: The counselor felt obligated to tell me that my brother would move away from me, and my sister would move away from me. Not physically but emotionally.

And that experience was horrible! I remember saying to myself how the hell do you know? Who the hell do you think you are? But when I went home, I began to look around, and I believe if you look you will always find what you are looking for. I found that my brother became more distant, and my sister became more distant. And my friends became more distant. To this date, I don't know if that would have happened anyhow but—. But I'm really sorry that the counselor did that.

Bonney: Do you think that they really did distance themselves from you or did you distance yourself from them as a protective measure?

Jacobson: Well, there my whole point is that you find what you are looking for, and you always create your own reality. My heart says, I may be wrong, but my heart says I distanced them more than anything else.

Bonney: Did you ever talk to them about that? Ask them?

Jacobson: Yes and no. I don't think they know. How could you ever know what came first? My hope is that nondisabled counselors don't do that today. Even if it's right, let the kids find out for themselves. That rehab center—that was really heavy.

Bonney: That really—?

Jacobson: Was a very heavy summer.

Bonney: Yes, I can imagine. Okay. Have we covered early childhood, young years, high school?

Jacobson: Yes.

Bonney: Yes. We can always come back if you think of something. Do you want to go on and talk about the Hofstra years?

— 20 —

A wonderful summer at Camp Jened

Jacobson: Before I talk about Hofstra, I have to talk about camp. I told you a horrible story about the rehab center. I've got to tell you a wonderful story about camp.

Bonney: Okay!

Jacobson: There was a camp in New York called Camp Jened.

Bonney: Camp Jened? Okay.

Jacobson: Jened. I can't believe that you never heard of it.

Bonney: Nope. I have not. [chuckles]

Jacobson: Everybody went there. Judy Heumann, everybody went there. I think Camp Jened was where most of us grew up. Camp Jened was run by hippies.

Bonney: Was run by—?

Jacobson: Hippies.

Bonney: Hippies! [laughter] Sounds good already.

Jacobson: You've got to understand there were other camps and I did go to other camps. But the other camps were run by nice non-disabled people. You know about nice, they were all nice. [chuckles] They were there to help the disabled and to give the disabled a good time. They were nice camps.

Camp Jened was not nice. Camp Jened was a wonderful camp. The people who ran it, they were there to have a good time. I can't tell you how wonderful it was for that to happen. It meant so much to be there and to know that the counselors were there not only because they were helping you, but because they are having a good time and you're there to have a good time with them, not for them, with them. It was such a powerful, powerful experience. This was right in the middle of the Vietnam War and the hippies were very political. They gave us a real good sense about how important it is to fight for what you want. It was the first time that I really felt equal. It felt wonderful.

They had parties—they had evening activities. About eight to nine, you could go into the woods with whoever you liked and have a good time.

Bonney: And did you do that?

Jacobson: Yes. [laughter]

Bonney: Repeatedly? [laughter]

Jacobson: I have to tell, I have to tell you one more thing.

Bonney: Let me follow up. You were introduced to relationships in this camp?

Jacobson: Yes.

Bonney: So you really did grow up here?

Jacobson: Just to give you one more example. I never knew how to kiss. One of the women counselors gave me a whole lesson in kissing. And I got to tell you that to date that was the best physical therapy. [laughter]

Bonney: And were these the kinds of things the counselors did? No wonder you liked it.

Jacobson: I don't know if anything like that exists today, but if it doesn't I feel sorry for disabled kids today. It was a really powerful, powerful experience.

Bonney: I imagine. Like you say, for the first time, you were equal.

Hofstra? Are you ready?

Jacobson: Yes.

Years at Hofstra, 1970-1974: PUSH, ABCD, and DIA boycott of President's Committee

Bonney: All right, why don't you tell me how you got to Hofstra [Hofstra University, Hempstead, New York]? What was the impetus to go to college? Not a lot of people in that time frame with severe disabilities went to college.

Jacobson: Ever since I started high school I knew I was going to go to college. Like I said I was a very heady kid. I graduated number eleven out of a class of about 1,200 kids. I was heady. So the question was not whether I would go to college. The question was whether I would go away to college. At that time, at that time, there were several colleges that took disabled students like the U of I [Illinois] or Hofstra. But you had to be a very, a very non-disabled disabled student. You had to prove that you could be highly independent. Did you do that?

Bonney: Absolutely. Yes.

Jacobson: What a bummer? Before I enrolled into Hofstra, I had to walk down a flight of steps to prove to the dean of students that I could get out in case of fire. Which is so stupid when you think about it. Can I tell you some stories about that? I was in college for about two months, and in the dorm in October the fire alarm went off at two in the morning. I was the first one out of the dorm. That's the good news! The bad news is that I was naked. [laughter]

Bonney: You got yourself out?

Jacobson: No. One of the guys on the floor ran into my room, picked me up, and we were out of there.

Bonney: Someone give you a blanket, I hope?

Jacobson: Yes, but it was cold. [laughter] Anyhow, the reason I went to Hofstra was, number one, they allowed disabled students to live in the dorm. Believe it or not that is the main reason. I really wanted to go away from home and, boy, am I happy I did. Hofstra was wonderful. I think I said that about high school. I was there for four years and it was wonderful. I never went home: I would stay year around. Yes. Once I moved away from home, the idea of going home I couldn't handle.

Bonney: Have you ever gone home?

Jacobson: Have I ever gone home? In the four years of college, I think I visited my home maybe three times all together. And then, be aware that as a disabled student, I was never angry at my parents. I believe I stayed away not because they were wrong, not because they were bad, not because they didn't love me, but because I couldn't handle it. I couldn't handle being without my wheelchair. I couldn't handle being without my independence.

Bonney: What was your major?

Jacobson: Math. Math and computer science. I did good. I graduated magna cum laude. I liked school.

Besides living there and besides doing well in school, I also worked for my whole four years. I got my first paying job the week after I started there.

Bonney: What did you do?

Jacobson: I worked in the pool hall.

Bonney: Pool hall?

Jacobson: Yes. [laughter]

Bonney: And what did you do?

Jacobson: Kids would have to pay, I think, a quarter a half hour to play on the table and I would take the money. When the half hour was over I would—

Bonney: Get the hook?

Jacobson: The point is it was not a glamorous job but it was a good, well paying job. I've got to tell you it was fun. I had a good time. And then, from there I became a security guard in the dorm. I would work graveyards.

Bonney: You did the graveyards?

Jacobson: Yes. Again, it wasn't a wonderful job, but it was a job. And then I worked in the housing office.

Bonney: Housing office? Okay.

Jacobson: And then, then the last summer I was there I was one of the summer managers in the dorms. Hofstra rents its dorms to different groups during the summer. The New York Jets football team is one of those groups. And I was responsible for their rooms and that was great. That was great.

[Interview 2: March 25, 1997] [Tape 3, Side A]

Jacobson: Okay, here we are again.

Bonney: Neil, when we finished up last time we had gotten up to about 1970 when you were about to enter Hofstra University. Can you start out by telling us how you got there, how you decided it would be Hofstra and your major and that sort of thing?

Jacobson: Okay, we spoke at the last interview about some of this. I knew that I wanted to go away to college and there were only a few schools that accepted disabled people in their dorm programs. Hofstra was one of them—almost. Before I got into Hofstra I had to prove that I could walk down a flight of steps. You remember we talked about that. Yes.

Bonney: All right, so you got into Hofstra and you were a student. What kinds of things did you do for extra-curricular activities?

Jacobson: I was very, very active. I got involved with the disabled student's program. They had an organization called PUSH, People United in Support of the Handicapped. From day one, I was very, very involved in that. Besides that I got a job, I got a job right away. I doubt I was there a week before I got a paying job working in the pool hall. We talked about that.

Bonney: Yes.

Jacobson: Besides that, besides that I was very involved with the computer club. What I remember is that I had a wonderful time from day one. I think I was there a week and I got acquainted with my first real girlfriend. Her name was Nadine. We are still very, very good friends. I just had a very good time. Oh, I also got involved with the wheelchair basketball team.

Bonney: What did you do with them?

Jacobson: I started out keeping score. And then about a half year later I became the assistant manager and then the manager. I was manager until I graduated. And I have to tell you it was wonderful.

Bonney: What did you do as manager?

Jacobson: I scheduled all the games. I was responsible for all the hardware. I was responsible that all the guys got to the games. I was responsible for finding money for the team. It was a wonderful, wonderful experience. We were a member of the national wheelchair basketball league, and I got to go to all the tournaments. I got to be on the board of the national league. It was great.

Bonney: Board of the national—?

Jacobson: League. It was fun. We always, always went out for pizza after the games. It was really nice bonding. I have very fond memories of the wheelchair basketball league.

Bonney: Let's go back. Tell me what you did with PUSH. This was about 1970?

Jacobson: We did a lot of work on campus. Made the campus more accessible. We finally convinced them to allow all disabled people to live in the dorms. We were very active on campus. I can remember arguing with the dean of students a lot—every week. It was a very, very nice way of really getting to know people and getting involved in school politics. We also worked together with the local organization. There was a local organization called the ABCD which stands for Architectural Barriers Committee for the Disabled. This was in Nassau County.

Bonney: Nassau County?

Jacobson: Yes. Hofstra is in Nassau County on Long Island in New York. There was a wonderful man named Hal Rosenthal. I don't remember how old he was but I think he was very old, like forty-five. [laughter]

Bonney: Oh, that old! [laughter]

Jacobson: I remember looking up to that guy as a real role model. He was a quad [quadraplegic]. He had a wife and two kids. That was a real eye-opener. He was a real guy doing real political work. He had a real life. We used to get together once a week at his home. For me as a kid in college it really meant a lot to have a role model like Hal.

Bonney: Are you still in touch with him?

Jacobson: No. Hal died. I think it was in my second year.

Bonney: Oh.

Jacobson: I took over chairing the committee.

Bonney: So you chaired it?

Jacobson: Yes.

Bonney: What kind of discussion—give me an example of the topics you would discuss with the dean.

Jacobson: Well, the obvious one was the one about the dorm—living in the dorm. I remember talking to the dean, the dean of students, and arguing how could they expect disabled people to go to college with the idea of going to work afterwards when you keep on calling them a fire hazard? To me it doesn't help your ego for someone to remind you again and again that you are a fire hazard. I remember arguing that life is a risk, and yes, if you live above the ground floor there is a risk and nobody is arguing that is not a risk. But that is what life is all about, is taking risks. It doesn't mean you're not careful. It doesn't mean that you do not think about safety—I have a high regard for safety—but there comes a point where you've got to decide this is the way it is. This is the risk I am willing to take. Those were the kinds of arguments I had with the dean.

Bonney: During this time then, were you part of the Disabled in Action?

Jacobson: Yes. DIA. Good old Judy Heumann again. What I remember is that each county had its own agency like I told you we had ABCD. But then around 1969 or 1970 Judy Heumann decided to organize an organization for the whole city and the whole state. That was DIA. I remember being there at the very first organizational meeting.

Bonney: Did Judy lead that meeting?

Jacobson: [laughter] The reason I am giggling, were you ever at any event with Judy where Judy wasn't the leader?

Bonney: Well, tell me what happened at that first meeting.

Jacobson: You know what? I have to be honest, I haven't thought about DIA for a long time. I do remember there being a lot of people, a lot of people, a lot of people in wheelchairs. I remember feeling very, very proud. It was the first time that I can remember feeling real proud of being disabled. Be careful. It wasn't the first time that I was in a big group of disabled people but it was the first time that we were responsible.

Bonney: What were you responsible for?

Jacobson: For getting the whole thing together. For talking about where we wanted the movement to go. And we were talking about a movement. It was not a social gathering, it was not a school gathering, it was not a medical gathering—

Bonney: A medical gathering?

Jacobson: Yes. It was a gathering of very alive disabled people who wanted to make the world better. It was a very exciting time.

Bonney: Did the DIA eventually usurp the individual county agencies? What happened there?

Jacobson: Yes, you know what, it's funny, I was thinking about that tonight at dinner. I was thinking about that tonight. I was thinking about how much I learned in my life. First at school—which was very confined. That is the way it was. School was a very confined universe. Arguing with the dean was wonderful. Wonderful. I learned how to argue on a one-to-one basis. I learned how to get things done for my school. Then ABCD was a little wider. I learned how to fight for parking for the disabled. Very local, local fights,

but they were fights nevertheless. I think the DIA was a very natural step up from that. When you say did DIA usurp the power. I hope not. I hope not.

Bonney: You said DIA—

Jacobson: When you asked me whether DIA usurped the power of the local, I hope not. I don't know what is going on today but I really hope, I really hope that PUSH is still there. I really hope ABCD is still there. I don't believe it is, but I hope that

each county still has their own local rebel. I believe that is how our people grow up. Do you follow me?

Bonney: Yes.

Jacobson: Like I said, I don't know what is going on now, but boy I tell you, I was so lucky to grow up in that era. Do you follow me?

Bonney: It is different now, isn't it?

Jacobson: Yes. Do you follow me?

Bonney: DIA was a statewide focus?

Jacobson: Yes.

Bonney: What were the first issues that you tackled?

Jacobson: I wish I had a better memory. I remember talking about architectural barriers a lot. I believe we were very focused on the physical environment because I think it was an easy one for people to understand. For ABCD we were talking about critical architectural barriers and I believe that is where DIA started.

Bonney: What did you see Judy doing?

Jacobson: [laughter] The same thing she does today. Her verbal skills are phenomenal. She is always able to put into words how everybody felt.

Bonney: Felt?

Jacobson: Felt. She is always able to get people excited about the movement. That was her power. Verbalize what people know and feel and then get them very excited about the movement and then get them working.

Bonney: Give me an example how she got people excited or working on a project.

Jacobson: If you are able to be with Judy for more than five minutes without getting a homework assignment, you are very unique. I'm halfway serious about that.

She has this uncanny ability of knowing what you want to do and then giving you very concrete assignments like call this guy, call that guy.

Bonney: At this time, was Judy a student at Hofstra?

Jacobson: No. Judy was a student at LIU, Long Island.

Bonney: Oh, okay. So she was a student at this point when she started the DIA. Did you hold office in DIA or did you ever take over at some point?

Jacobson: I don't think so. I've got to tell you that I don't remember that part. I remember more of ABCD because the death of Hal was heavy. That was heavy, that was very heavy.

Bonney: Sometime, now maybe I have the time sequence wrong and you let me know, was this about the time that you boycotted the President's Committee [President's Committee on Employment of the Handicapped]?

Jacobson: Yes.

Bonney: Would you tell me about that?

Jacobson: Yes, I was a freshman in college. Every May the President's Committee held a meeting and they usually had about 300 people. A group of us from PUSH, I think, maybe eight of us, got into a car—

Bonney: Eight of you in a car?

Jacobson: Yes, and we drove to Washington. I remember the President's Committee meeting was very pompous. They were very well orchestrated but very pompous. They were all non-disabled people. Can I tell you one story about that? They gave an award, they gave an award to the handicapped guy of the year. And I got to tell you, here we are for two hours sitting and listening to all these non-disabled, white men talk about whatever the hell they were talking about. Nothing meaningful. Finally, there was this one disabled guy who was going to get an award. I think, okay, now this guy is going to talk about housing, or transportation or architectural barriers or something like that.

[Tape 3, Side B]

Jacobson: So, finally they've got this guy who got the award and they spoke about how wonderful he was. They gave him the microphone and all he said was thank you.

Bonney: [chuckles] Can you remember who this man was?

Jacobson: [laughter] No, but I cried. I cried. We finally got our big chance to talk about real things and all the guy said was thank you.

That night, that night the disabled people that came down from New York, we had an all-night vigil at the Lincoln Memorial. That was heavy, that was pretty heavy. In the morning we just did not go back to the President's Committee. That was heavy.

Bonney: What was the purpose of the vigil?

Jacobson: To make the public aware of what was going on in this country for people with disabilities. I've got to be honest with you, there might have been a bill in Congress, I don't know. It was very heavy.

Bonney: Was Judy one of the people?

Jacobson: Of course. Yes.

Bonney: Yes? Was the vigil her idea? How did it come about?

Jacobson: It was her organizational skills.

Bonney: Did you do this on the spur of the moment or had you planned this when you went to Washington?

Jacobson: I don't remember. I'm sorry.

Bonney: That's okay. Did the police allow this? How did they react?

Jacobson: You know, as I think about it, I think, I think, I think it was planned because I do believe that we did have a permit.

Bonney: You did have a—

Jacobson: A permit. Also I remember in the morning, we walked from the Lincoln Memorial to the Capitol. And I remember I kicked all the way.

Bonney: You—

Jacobson: Kicked.

Bonney: You kicked?

Jacobson: Yes. Don't forget that I still don't have a power wheelchair at this time.

Bonney: Oh, okay. Pushed yourself, you mean, by kicking.

Jacobson: I don't know why, I don't know why, but it never bothered me to kick all the way. I'm still not sure why, but I remember very vividly that I wanted to kick. And I kicked. I really don't know how—I think it was only about five miles. Is that it?

Bonney: It's a long way. Yes.

Jacobson: But there was something about being out there with all the other disabled people that I felt extremely proud.

Bonney: How many people were at the walk?

Jacobson: I remember a couple of hundred.

Bonney: What did you do during the night?

Jacobson: Got cold. [Laughter] I remember being cold and McDonald's. McDonald's donated a whole bunch of hamburgers.

Bonney: Did you have press coverage for this?

Jacobson: Yes.

Bonney: What kind of coverage?

Jacobson: I believe it was *The Washington Post* and *The New York Times*.

Bonney: So Judy organized this whole thing.

Jacobson: Of course.

Bonney: Judy organized it from New York?

Jacobson: Of course, there was one other trip to Washington that I will never forget. We hired a couple buses to take us down to Washington to lobby for a bill. What I remember the most is that we got there fifteen minutes after they voted against the bill. I have to be honest, I don't remember what the hell the bill was. But that was one of those things that keeps going through your mind—because there is no way of hiding, no way of kidding yourself. You flunked.

Bonney: Flunked?

Jacobson: I remember us going home on the bus and saying to myself, Yeah, that failed badly today and tomorrow we will be better.

Bonney: Was this a Judy activity again? Where did DIA get its money to do these things?

Jacobson: Again, I don't know.

Riding the New York subway

Bonney: I've been told that there is a story about you on the New York City subway. Do you know what story I am alluding to?

Jacobson: Which one?

Bonney: All I know is something about going up the stairs by the seat of your pants.

Jacobson: I did that a lot. You have to understand that in New York at that time, not only was it not accessible but there was a law that said you were not allowed to use the subway. Are you aware of that?

Bonney: There was a law? Not allowed to use the subway if you are disabled?

Jacobson: I used the subway a lot. The way I would do it is I would go to the subway and begin going upstairs on my butt with the idea that somebody was bound to see me, bound to help me. Instead of getting into a whole big dialogue with people who probably can't understand what the hell I am talking about anyhow, I found it was quicker to begin going up the stairs. Somebody would see me and see the wheelchair and figure out that oh, he needs help. That always worked and that is obvious because I am here today.

Bonney: Now, I'm not real clear. You took your wheelchair to the subway station, okay. And then you got out of it and crawled up the stairs. Someone would take your chair up for you, or down as the case may be?

Jacobson: Yes.

Bonney: Then how were you allowed on the train?

Jacobson: Oh, that was the easy part because once you're up there and once you're back in the wheelchair, it was no problem to get on the train. The problem came with the police because if the police saw me go upstairs or downstairs they would stop me and give me a hard time.

Bonney: So if no one saw you, then you could get on the train and go.

Jacobson: Yes.

Bonney: Did you work towards getting that law revoked?

Jacobson: To be honest, no. Because in my mind it was a stupid law. It was a stupid law and the real problem was not the law. The real problem was the barrier. For my mind, why would you bother revoking the law?

Bonney: You couldn't use it anyway.

Jacobson: Yes. What I remember the most was that very often when the cops stopped me I would give them the number of one of my professors at college. I found that once they believed that I was, indeed, a college student and not a runaway, not a runaway from the local institution, they would stop harassing me.

Bonney: So was your going up and down the stairs purely to get on the train to get where you wanted to go? It wasn't a political statement?

Jacobson: No. Even though everything is a political statement, using the subway was actually an easy way to get around.

— 31 —

The move to Berkeley, 1974

Bonney: Let's move on to your Berkeley years. I think we are up to 1974 when you came to Berkeley. How did you make the transition from New York to California?

Jacobson: Sharon, I came out here on the red-eye. I got here on Friday morning about four A.M.

Bonney: Friday morning?

Jacobson: Friday morning, and I didn't know anybody. All I knew was that I had a room waiting for me at the I-House [International House]. Do you know where the I-House is?

Bonney: Yes.

Jacobson: I got to the I-House probably about seven in the morning. I got in my room and I took a nap. I woke up about noon and decided to take a walk. I went down to Telegraph Avenue and I went into Larry Blake's. Remember Larry Blake's?

Bonney: Yes.

Jacobson: I ordered French toast—

Bonney: French toast?

Jacobson: And coffee, and when it came out it was all cut up and there was a straw in my coffee. [laughter]

Bonney: You had arrived! [laughter]

Jacobson: Yes, I was in heaven. When I saw that straw in my coffee, I can't tell you how ecstatic I got. It was like, this is heaven.

Bonney: Now did you come up—oh.

Jacobson: Then after I ate, I went outside on Telegraph Avenue and I ran into Ed Roberts. You've got to hear this. I was still kicking. Ed came up to me and said, "Who are you?" I said, "Neil Jacobson." He said, "Why are you kicking? Why don't you go up the street to PDSP [Physically Disabled Students' Program] and borrow a power wheelchair?" So you know me, I figured hey, if it was okay for this guy, I can do this too. He invited me to his home later that day. You could tell that Friday was a wonderful day. Anyhow, I went to PDSP and I did, indeed, borrow a power wheelchair, my first power wheelchair ever. I went back to I-House, I don't remember why, but I went back to I-House and then I went out again. I-House is on a big hill. The only way I could control my new power wheelchair was to run into parked cars.

Bonney: Run into—

Jacobson: Parked cars.

— 32 —

Bonney: Parked cars! [laughter] Or else you'd go off the curb!

Jacobson: There I was coming down Bancroft hitting every other parked car. Then I went to Ed's home. It blew my mind. I never saw an iron lung before. The next day I had a part-time job working at CIL [Center for Independent Living].

Bonney: You had a part-time job when you came out?

Jacobson: No, no. That night—

Bonney: Oh.

Jacobson: That night when I went off to visit Ed he hired me to help with a study of the state of the art of literature and people with disabilities. That was my first day in Berkeley. I've got to tell you, I've got to tell you with a day like that I knew I made the right decision in coming to Berkeley! [laughter]

Bonney: PDSP at that time was up behind Top Dog?

Jacobson: Exactly. It was wonderful. It was wonderful. I used to go there once or twice a day. It was my local hangout. It was wonderful. They always had food. They did.

Bonney: Yes, Zona cooked. How did you get up the ramp the first time?

Jacobson: I kicked!

Bonney: You could do it?

Jacobson: I kicked.

Bonney: It was pretty steep, wasn't it?

Jacobson: I was a good kicker.

Bonney: What did PDSP look like? When you went in, what did you think?

Jacobson: You know what, I can still see it in my mind. There was an area, a big area in the front and there was a kitchen. Behind the kitchen John Hessler had an office and there was another guy—

Bonney: Another guy?

Jacobson: Another guy in a wheelchair. What was his name?

Bonney: Don Lorence?

Jacobson: Yes. There were always people there. Always people. That is where I met Scott [Luebking]. Scott was a graduate student. We became very, very close at PDSP. I don't know what is going on today, but, boy, I was lucky. It was a very warm, wonderful place.

— 33 —

Bonney: Did you come to Cal as a graduate student? In—

Jacobson: Yes. Computer science.

Bonney: And did you stay at I-House the entire time?

Jacobson: No. I was the first student to live in the dorms. That didn't sound right. The year I began, was the first year they began the dorm program. I believe there were four disabled guys in the dorm, but I have to be honest, I don't remember the other four.

I have to tell you the dorms at Hofstra were better.

Bonney: The dorms at Hofstra were better?

Jacobson: Yes.

Bonney: Better than the dorms here. Why?

Jacobson: Here, the dorms are right in the middle of the city. At Hofstra, Hofstra was a very well-contained campus. I have to be honest, when I went for my BA, I am very, very happy that I did go to a contained school. Do you know what I mean by that?

Bonney: No. Can you explain more?

Jacobson: I think, I think I knew everybody, everybody in the whole school because there was nowhere else to go. So people hung out on campus and in the dorms. Can we take a break?

[tape interruption]

Jacobson: I was saying that in my four years of undergraduate work I really appreciated being in a very self-contained school. I believe the students got to know each other better and there was a real school spirit. Living in Berkeley, because you were right in the middle of the city, I think it made it harder to get to know more of the kids. I was only there one semester.

Bonney: I was going to ask you if during that semester you were there did you use the attendant program, the Residence Program services?

Jacobson: Yes.

Bonney: Were they helpful?

Jacobson: Were they helpful? I've got to tell you, one of my attendants is still now one of my very, very best friends. Were they helpful? Yes, I met some wonderful people.

Comments on Ed Roberts and John Hessler

[Tape 4, Side A]

Bonney: For the one semester that you were in the Residence Program, and I am assuming using PDSP's services, what did you see Ed Roberts doing?

Jacobson: Ed was still at CIL. He was still the big guy, the big guy, and everybody knew he was the big guy. He knew he was. He had his own style of management which was not to manage, but you knew he was in charge. It was very funny. Unique. I have never had a manager like him before or since. Not very well organized, not very directive, not very structured at all but you always knew what he wanted. He always did a phenomenal job. Phenomenal. He was always a wonderful speaker and I always admired that. Like Judy Heumann, he was always very verbal. He always knew how to move an audience. Could I say one more thing about Ed?

Bonney: Sure.

Jacobson: Now that he has been gone for a couple of years, I think I have more respect for him now than ever before. I believe that there are very few leaders in our country and I believe that Ed was a real leader. And what I mean by that—he knew where he wanted to go, he knew where he wanted the movement to go, and he knew how to get people excited about going there. That's a real leader. That's number one. Number two. If you had your idea of where you wanted to go or where you wanted the movement to go, he had the amazing ability of making you believe that you have power to get there.

Bonney: Can you give me an example of how he behaved—?

Jacobson: If you take a look at CIL or WID, you'll see a lot of very disassociated projects and if you look at it from the outside it is very confusing. You think about the AIDS project, or the International Project and you wonder how does—why are they all there? You find that they are there because people believe there is a need for AIDS work and people believe that there is a need to help in international work. Ed's real power was to understand what you wanted to do and to help you get there. Do you follow me? Like I say, I believe that the real leader will take the time to understand where you are, what you want and help you get there. I admire him for that. Did you get that?

Bonney: Yes. In the same vein, what kinds of things did you see John Hessler doing?

Jacobson: I remember John as very different than I remember Ed. I remember John was the guy I would go to if I needed help, or to talk. What I am saying is that I would go to Ed if I wanted somebody to get me excited or to get me revved up. I would go to John if I needed somebody to be quiet with.

Bonney: Give me an example of the kinds of things you went to John about.

Jacobson: If I had a bad day, a bad day. I remember going to John and saying, "I had a bad day." You know what I mean?

Bonney: Yes. How would he respond?

Jacobson: With quiet, he'd say, "Why was it bad?" You knew he was there. You know what I am saying?

Bonney: More like a confidant? Or a big buddy?

Jacobson: Yes.

Bonney: Did you see him running PDSP?

Jacobson: Well, what do you mean by that?

Bonney: Did you see him in a management role there, or did you observe him leading meetings or being a manager or a leader?

Jacobson: The reason I am hesitating is that he did run the program [chuckles]. That is a fact, he ran PDSP. Did I see him do that, of course I did, but he was not pretentious.

Bonney: He was not pretentious? What would you say was his leadership style?

Jacobson: That was it. That was it. He was there, he was always there for you.

Bonney: Did you see him develop new services at PDSP?

Jacobson: The answer is obvious, yes. But that is not what I remember him for. Do you follow me? That is not what I remember John for.

Bonney: You remember him for his listening and support. At this time was Judy around?

Jacobson: No. She was back in Washington working for Senator [Randolph Williams]—she was working for some senator.

Bonney: When you were in the Residence Program for that one semester, who headed it up? Was it Susan O'Hara?

Jacobson: No.

Bonney: Can you remember who it was? I don't know who it was or I would help you out here.

Jacobson: No. I can't think who it was. I would be very embarrassed if it was.

Bonney: So whoever it was, they didn't make a very big impact on your life for that semester.

Jacobson: I really don't remember anything at all—that is weird.

Bonney: That is all right. Did you serve on committees or do anything with PDSP?

Jacobson: No, I got involved right away with CIL. PDSP was where I hung out and CIL was where I worked.

— 36 —

Bonney: Neil, what were SARs?

Jacobson: SAR stands for Sexual Attitude Reassessment. It was a program started in the seventies to help people look at their sexual attitudes. It was a three-day workshop held monthly primarily at the School of Sexology in San Francisco. Groups of up to 100 people would gather for a weekend to hear panels discuss different aspects of sexuality. There was a panel on gays, lesbians, S&M, aging, massage, parenting, adolescents, and, of course, disability. Almost immediately after arriving in Berkeley, I got involved as a regular member on the disability panel. It was great fun and a great way to meet people.

— 37 —

II. Professional Work and Affiliations; Adoption of David, 1974-1997

Computer Training Project: start-up, goals, student requirements, 1974

[Interview 3: April 8, 1997] [Tape 5, Side A]

Bonney: Neil, I think we should talk about your years with the Computer Training Project and how that came about. Can you tell me how you got involved with it?

Jacobson: Okay. This whole idea came from IBM [International Business Machines]. In 1970, I think, a man who worked for IBM broke his back and became a para. After his rehab, he decided IBM ought to start a program to teach homebound, disabled people how to become programmers.

This is back in Virginia. They began a program in a rehab center back there. I don't remember its name. But anyhow, they began a program, a dynamite program in a rehab center in Virginia for about five guys. All the five guys stayed in the rehab center for nine months: and, then when they graduated, they could get jobs back wherever they came from. Then IBM came out to California with the idea that if they could do it once they could do it twice. They got together with the Department of Rehab [California State Department of Rehabilitation] in California. The Department of Rehab got together with CIL and CIL thought it was a wonderful idea. But instead of having it in a rehab center, they wanted it in the community and they wanted to hire a couple disabled people to teach programming and who could run the school. There were only a couple in the whole city, and we got hired. So that is how it began.

Bonney: So you were hired. Who was the other person?

Jacobson: First they hired Scott [Luebking]. Scott was hired as the director and Scott hired me to be his assistant. So that was how I got hired.

Bonney: What year was this?

Jacobson: 1974. Well, we were hired in the middle of October and we started the end of October and February 4, 1975, at 9:08 in the morning we had a whole class.

Bonney: So you did it from October to February. What did you do during that time period? What did you have to do to make a program?

Jacobson: First, we had to find a place, we had to find students. That was a lot of fun. We went to all these rehab centers, all these VA hospitals, all these rehab organizations finding students. We had to find a place to hold the school, we had to find computer equipment, and put together a business advisory committee and put together the whole curriculum. And I have to tell you something, those ninety days, it took us ninety days, and I've got to tell you it was a kick. It was wonderful. We didn't know what the hell we were doing. We didn't know what the hell we were doing, and we did it with lots of enthusiasm.

Bonney: Now, who worked with you from the Department of Rehabilitation?

Jacobson: John Velton was from the Department of Rehab and IBM gave us a man named Joel Parker. A good guy, a good guy. Joel was primarily responsible for putting together the business advisory committee. Joel got together, I figure it was about eighteen companies in the Bay Area—Fireman's Fund, IBM, Wells Fargo, B of A [Bank of America], Levi's [Levi Strauss and Company], all the big guys.

I will never forget the first meeting we had of the business advisory committee which was at Fireman's Fund. You've got to imagine this. Scott, you know Scott, he's a quad. When he gets nervous, he spasms. Whenever I get nervous, I mumble. So there we were in front of this auditorium filled with business people. Scott is almost horizontal because of spasms and I can't talk a goddam sentence. It was something. We had a good time.

Bonney: So how did you get through that first meeting? What did you do?

Jacobson: Like I said. Like I said he spasmed and I mumbled. [chuckles]

Bonney: What were the goals for the advisory committee?

Jacobson: I didn't make—what did you mean, what were the goals for the program?

Bonney: Well, what did you all hope to gain by having an advisory group? What was their role going to be?

Jacobson: Before I answer that, let me tell you what the goals of the program were and then I think the goals of the business advisory committee becomes obvious. The goal of the program was very, very clear. The goal of the program was that all the graduates were going to get full-time jobs in the private or public sector as entry-level programmers. That's very clear. That's what I love about the program. The goal was very distinct. The goals were very explicit. All the people had to live on their own. They had to have all their attendant care taken care of: they had to have all their transportation. Because in order to go to work you've got to have your act together. Do you follow me?

Bonney: Yes.

Jacobson: What I loved about the program was that we helped folks become independent under the umbrella of going to work. To this day, I love that whole idea. Do you follow me?

One other thing is, if the goal was only to go to work or only doing programming, you could go to any school. You could go to Cal, or you could go to a JC [junior college] or you could go learn programming almost anywhere, but what we did was worry about the whole human being. You follow?

Bonney: When people applied to the Computer Training Program, did people have these skills when they came, or was this something that you had to teach along with programming?

Jacobson: Exactly. Yes. Most of them, I would say, did not. I really believe that is why they came to CTP. People who had their act together—they could go anywhere. It was the people who need a little more attention, a little more kick in the ass, a little more motivation—that is where the power of the program comes in. Do you follow that? That is why I really loved working for CTP, was because we did look at people, at the whole human being.

Bonney: What were the criteria for a person to get into the program? What were your requirements for them?

Jacobson: They did have to pass a couple of aptitude tests. They did have to have a high school diploma. They did have to have, I forget all the criteria. But besides the ones we put down on paper they had to pass an interview with me or with Scott. I was looking for a gleam in their eyes, some kind of motivation. That was my criteria. And the other criteria was that they had to have a significant, physical disability. So that was the goal of the program.

The goal of the business advisory committee was, well, the real goal was to help find jobs. That was the ultimate goal. But besides that, they had to approve the curricula. They had to test every student orally every three months.

Bonney: They had to test every student—

Jacobson: Orally.

Bonney: Once a year, once a semester. What was the test?

Jacobson: Three times in the nine months, and they had to provide work experience. The reason for all that was to give them and the students one-to-one contact. We wanted to make sure the program was as real as possible. So that was the goal of the business advisory group. In my opinion it was a very hard program. It is a hard program. I keep feeling that if you can survive nine months at CTP, you can do anything. That was my whole philosophy: do this and you can do anything. You could work ten, twelve, fourteen hours a day five, seven, or eight days a week. Again, this was my way, our way, of telling them that they could do it. That if they wanted something, it's theirs. Programming. I've got to tell you I love programming. You know why?

With the program there is a beginning and there is always an end. The program either works or it doesn't. If it doesn't, you can always figure out why. If it does, you can go home and feel wonderful. And I love that positive feedback.

Bonney: What was the success rate?

Jacobson: Right now, there are about 400 people who graduated and about 92 percent are working. Ninety-two percent. That's not bad. But you have to be careful, I said 92 percent of the people who graduated. Only about half the people who began, graduated. So statistics are deceptive—I could do anything with statistics. The people who didn't graduate, it is not obvious to me that they did not succeed. Some of the people who dropped out, dropped out because they made a very good decision that this wasn't for them. For some of them, it was a good decision. I call that a success. Do you follow me?

Bonney: They learned a lot. I want to go back to something that you said originally. When the fellow came from Virginia, with the first program, that the idea was to train people to be programmers, who would then go back to their homes and become homebound workers, the term you used at that point. But, this program did not develop into homebound workers. How did that change come about?

Jacobson: [laughter] Can you imagine talking to Ed Roberts about homebound programs?

Bonney: So Ed was the person that IBM was talking to first?

Jacobson: Well, Ed and Scott and I knew from the moment we heard that, we were like, Wait a minute, that's not what we wanted. That's the reason it got changed, because of the whole Berkeley environment. The whole independent living movement philosophy.

Bonney: And IBM bought the philosophy when you posed it to them?

Jacobson: We didn't even get into an argument with them. Yes, they did. They really did.

Bonney: When you were interviewing students for the program, did any of them get turned down? Did you ever say, "No, you can't come into the program"?

Jacobson: Yes.

Bonney: You did. Very often?

Jacobson: No. Scott was a lot better than I was.

Bonney: At letting them in or keeping them out?

Jacobson: Keeping them out. [laughs] It was hard for me to say "No." Could I give you one story about that? This is a good story. One woman came and she said that she had a little back problem and that she was in pain most of the time because of it. I have to tell you that she was a beautiful woman. I said, "Wait a moment, this is a program for significantly disabled people." I said "No" on that basis. And she argued and she won the argument. It turned out she was, indeed, one of the more significantly disabled. She could only sit about a half hour at a time. Being one of the best students, she got a job and then she came back and took over for me when I left.

Bonney: When did you become the director of the program?

Jacobson: Scott was there for only two semesters. When Scott left I became the director.

Bonney: So that was in 1976?

Jacobson: Something like that.

Bonney: What was your relationship with John Velton during this time?

Jacobson: Even though I worked for CIL, John was really my boss. John was the guy who gave us the contract from the state. John was really the boss. John was really the one I went to if I had problems; if I needed counseling or advice. John, well you know John, John is one of the nicest, kindest guys I know. I really appreciate John a lot.

Bonney: He was supportive of the program?

Jacobson: To go back to that first meeting at Fireman's Fund. John was the one who calmed people down—

Bonney: This is while they watched Scott spasm and you mumble?

Jacobson: He always, always had a kind word. Always knew how to make people feel comfortable. I always appreciated John.

Blind/Deaf component dropped

[Tape 5, Side B]

Bonney: Neil, as part of the CTP program, and I am not sure if it came in while you were the director or after you were the director, you had a blind-deaf component to the Computer Training Project. It didn't work out. Can you tell me about that?

Jacobson: That didn't work out. That didn't work out. Like I said, I wanted to take significantly disabled people, and people who are blind and deaf, I think qualify for that category. There was a guy who was blind and deaf who worked for the government. Did you know that?

Bonney: No.

Jacobson: His name was McDonald. I don't remember his first name. Anyhow, I found him. I don't know how the hell I found him, but I found him. I convinced him to come to California. He found two blind-deaf students for our program. It didn't work out. But I remember having a good time.

Bonney: What I heard was there were problems—that there would be times when the blind/deaf students would need more time devoted to a topic or an issue or whatever it was you were studying and that was somewhat slowing down the rest of the group. That became a problem. Do you have a recollection of that? Is that your opinion of what happened?

Jacobson: Yes. It is hard to slow me down. One of my philosophies, and I don't know if I still believe it, but at the time, one of my philosophies was we had to be better than non-disabled people. Why? Because that is life. To me, I don't care what the hell you look like, a para, a quad, a person with cerebral palsy. I believe that we had to be better, we had to work harder, we had to perform better. I don't think I was willing to slow down for anybody. Does that answer—?

Bonney: Well, let me probe a little more because the story I got is, that John Velton, at one point, felt he had to make the decision that blind/deaf students would no longer be in the CTP program and that then happened. There were no more blind/deaf students in the program. I wonder if you could talk to me about your feelings about that or what went on, number one, and I wanted to ask you about a program that did develop for blind/ deaf students in Ohlone College. I wondered if you played a part in establishing that program. So first of all, can you tell me did John, indeed, make the decision that blind/ deaf students would not be in CTP and how you felt about that?

Jacobson: I did not necessarily always agree with John. [chuckles] There were a few times that John and I did go head-to-head. This was, indeed, one of them. I believe this guy, McDonald, he did go to Ohlone with his students.

Bonney: With his students? McDonald, who was a student, went to Ohlone—?

Jacobson: No. McDonald is the guy who used to work for the government. I believe that, I know that, the reason he went to Ohlone is that Ohlone allowed them to go at a slower pace.

Bonney: I want to clarify. McDonald was in the CTP program originally. Okay. Then he left there and went to Ohlone? There was already an established program at Ohlone?

Jacobson: No. He started the program for other blind/deaf. I believe that he did that for a couple of years and then it died.

Bonney: Did you help the Ohlone College set up the program at all?

Jacobson: No. Again, again, I did not agree that allowing them to go at a slow pace was going to benefit them. It might make them feel better but as far as finding jobs at the end—that wasn't my philosophy. Do you follow? I really believe that if you want to go to school and go to work then you better work your you-know-what off and be competitive.

Program focus changes

Bonney: There are some negative feelings currently about the CTP program in the fact that it is a segregated program at a time when we are talking integration and no more separate but equal, et cetera. What is your response to people who put that out there as an issue?

Jacobson: Okay, I have negative feelings about CTP now, also, but not because of that. I'm going to talk about that before I answer your question and then I will answer your question. My feeling is that the students are not significantly disabled now. My feeling is that the power of the CTP of looking at the whole independent living aspect has gone away, and now they are focusing only on programming. Because they are only focusing on that one main aspect, that is where my criticism comes in. If you are only focusing on programming or whatever, you are right, they could be going anywhere, but if you are focusing on the whole independent living aspect and if you look at programming as one excuse, an excuse, for doing all of that then you have a whole new ball game. Did you follow that?

Bonney: So they are not taking people in anymore and getting them ready for independent living. They already have to be living independently to take the program, at this point, and that is why they are not as severely disabled?

Jacobson: That's part of it. Let me tell you what I think happened because I think that this is a fascinating phenomenon. The program was successful and people expected it to continue to be successful. In the end, the businesses expected it to continue. Therefore, the criteria began to get harder and harder and, therefore, almost unconsciously, less significantly disabled people came in and the criteria continued to go up and as it went up, less significantly disabled people came in and the criteria continued to go up. There was almost a spiral effect. It's a fascinating phenomenon to watch. Even though I was watching it, there was nothing I could do about it. I don't think there was anything that anyone could do about it.

Bonney: Are the criteria too high now? Is that a problem?

Jacobson: Yes.

Bonney: How would you fix it?

Jacobson: I sincerely believe the programming is too hard, too sophisticated. I'm not sure programming is the right career anymore.

Bonney: So the focus of the program should change from where it used to be?

Jacobson: Programming is a pretty highly skilled profession, and most people with disabilities are normal. I think we need to pick something more normal.

Bonney: More average than the highest achieving—yes.

Jacobson: It's almost like, if you have the ability to be a programmer then the possibilities—you are well along on your way up with life anyhow. We have to become more normal, more average.

Bonney: Like what?

Jacobson: Believe it or not, I do have an answer to that. This is a whole new area but we can talk about it anyway. I believe that disabled people have to start thinking about running their own business. Today, in the United States, most of the new jobs are in small businesses. Most people begin their life, begin their career in a small business and a small business can be anything. It could be delivering newspapers. That is a small business. What I would love to see CTP do is help them start their own business—whatever they want. Do you follow me? This is my goal. I always wondered why we do not focus on economic development. I can't explain why, but we are the only minority I know that doesn't promote its own business. We are the only minority I know that gives away our money. If you look at the economics of the whole country, the economy would be very weakened if there were no disabled people, but we don't use our economics, we give it away.

Bonney: We, meaning disabled people?

Jacobson: Yes.

Bonney: How do we give it away?

Jacobson: Whenever you buy a wheelchair from a non-disabled-owned business, we are giving our business away. Whenever we hire non-disabled attendants, or personal assistants, you are giving our money away. Whenever we have a conference in a non-disabled-owned hotel, we are giving our money away. That is what I am talking about. If you look at the women's movement or look at the black movement, they had a focus on business.

Bonney: You said that this is something you would like CTP to do. Isn't this what the World Institute on Disability is moving into? Let's talk about that. You are on the board of the World Institute. What is going on with WID in terms of economic development and what are your feelings about it?

Jacobson: Well, I think I already described most of this. One thing I find very ironic or one thing I don't understand, on the one hand we say we are independent, we can do anything we want. But on the other hand, we say please hire the handicapped or the disabled. We are still waiting for the white man to hire us. We are still giving the power to white, non-disabled men, and I find that so ironic.

Bonney: What would turn that around? What should people with disabilities do?

Jacobson: Like I said, I think we can learn a lot from the black movement, from the Jewish movement. Promote our own business, promote our own economics, make our own money work for us. We are not very business-savvy. I am very happy to say that the World Institute on Disability is looking, on a policy level, at the policies that work against us. There are some, not many, but there are some and the World Institute is looking at that. They are also beginning to work on how to promote disabled businesses.

Bonney: Is this something that you are going to be involved with as a board member?

Jacobson: I hope so. This is my reason for being on the board. I believe this is the next step and I am very, very excited that we are doing this.

Bonney: This was the last thing that Ed Roberts was working on before he died. This is one of the things he wanted to happen. Great.

Changing computer technology

Bonney: Let me go back and ask one question about CTP and then we'll talk about WID. What do you think are the effects now of the new computer technology on that program?

Jacobson: Can you give me a hint?

Bonney: There are new kinds of computer equipment that is voice-activated, or eye-activated, or it does so much more for us now than it did twenty or twenty-five years ago when CTP was started. Computers have made the disabled person's life a lot easier to communicate and do things. Does all that technology affect the Computer Training Project at all?

Jacobson: Yes and no. How about that. How about that. Computers are only an excuse. No, that is not true.

Bonney: That's not true?

Jacobson: There is no doubt that computers have opened a whole variety of new jobs.

[Tape 6, Side A]

Bonney: Neil, we were talking about new computer technology and its effect on the CTP Program. You had just said that it was true that computer technology had opened a lot of new job opportunities for people with disabilities.

Jacobson: But, but the job opportunities were always there. I don't know how to explain this. If you want to work, you will work. Computers may make it easier, but that's not the real issue. Do you follow me? I have been trying to explain this to the Computer Program for twenty-five years, and I'm not doing a real good job here either. People will work, will find work. There is no doubt that computers will make it easier. But what I can't find is what is it that makes someone want to go to work, what is it that makes someone want to wake up in the morning. Do you follow me?

Bonney: A motivation. An internal push of some sort?

Jacobson: To me that's the real heart of computer programming. The computer itself is only a machine. A tool. Do you understand?

WID: think tank and money issues

Bonney: I think I do. Yes. Let's go on to WID. We talked about it a little bit. Can you tell me when you joined WID's board and how you got involved with WID?

Jacobson: I've been on the board for four years now. When I resigned from CTP, I was on the WID board. I've been involved with WID almost since the beginning because of my contact with Ed, my contact with Judy and my contact with Joan [Leon], et cetera.

Bonney: That was back in 1983 when that started?

Jacobson: Yes. I've got to tell you that I really love being on the WID board. I'm having a wonderful time in a weird kind of way.

Bonney: Now, you are the vice chair?

Jacobson: Currently, I am the vice chair and I am almost sure that I will become the chair in a couple weeks.

Bonney: Congratulations!

Jacobson: WID allows people creativity. WID allows people who have an idea to run with the idea. I've got to tell you I love that. If you have an idea about how to make personal assistance services better and you want to do something about it; WID, I hope, will help you develop your idea to move it along, to give others a little bit of hope. And really help you develop that. Wherever your heart is, that is where WID will help you go. I have very high hopes for where WID will go.

Bonney: WID has been talking about becoming a "think tank." Do you think that is where WID is headed?

Jacobson: For one thing, I think that is what WID is now. I think that is what WID has been. Like I said, if you have an idea about something and you want to talk about the idea, then you call that being a "think tank." That's my idea of a think tank. It may not be very sophisticated or professionally run but it is very exciting and dynamic. I believe that WID ought to be a real think tank. My hope is that people all over the world, all over the country, if they have an idea about how to make life better for people with disabilities, that they will come to WID for a year or two and develop that idea.

Bonney: WID is having some financial problems at the moment as we are all aware of.

Jacobson: You're kidding! [chuckles]

Bonney: What is going to happen to WID?

Jacobson: Okay. One of the things that I am very embarrassed about, about the whole movement, is that we, as a movement, we don't know that much about money. We spoke about that about fifteen minutes ago. I think WID is a wonderful example of that. WID exemplifies the whole movement—we don't know how to command money. We don't know how to grow money. We don't know how to build our money. Do you follow me? Like I said, I look at the financial problems we are having as very symbolic of where the movement is. We know how to get grants, we have no problem getting grants, but grants are another way of putting out your hands and saying "I want, I want, I want." But we don't know how to bring in money and have that money work for us.

Bonney: You mean private money—non-governmental money.

Jacobson: Yes. We don't know how to make one dollar become five. I look at this as a big challenge. I really believe that we have to learn how to command and grow our own money. That is going to be my focus the next x-number of years.

Bonney: Do you think Ed Roberts knew how to command money?

Jacobson: No. No. No. No. The guy knew how to ask for money but that is not the same thing. That is not what I am talking about. I am talking about not only asking but growing that money. And you know what, I almost think that people with disabilities are embarrassed with money, and I find that fascinating. That is one of the things that I am hoping WID will begin to study. Why are disabled people embarrassed with money? If you look at the other movements, again, the women's movement or the black movement, you don't see that same kind of phobia about money.

Bonney: Do you think it is because most disabled people never had any or had very little?

Jacobson: No, I don't think that is it, because if you look at the immigrants that came to this country, most of them were poor; but, yet, there wasn't this phobia and I do believe that it is a phobia.

Bonney: As a public policy research organization, what do you think WID can do to study this issue or to get people over the phobia or move the cause forward in that area?

Jacobson: Again, the reason that we have been successful about removing architectural barriers or transportation or housing is that we have been able to raise awareness. I believe that the next wave, the next era will be political awareness that it is okay to have money, it's okay to promote your own business, it's okay to grow your own money. So I think it is a matter of making people aware.

Bonney: In other words, trying to open the window for them to look through; they could be doing this sort of thing with a mind-set change or a goal change?

Jacobson: Yes, exactly.

Bonney: Is that something you hope WID will do?

Jacobson: Oh, yes. [laughs]

— 48 —

Bonney: Where do you hope WID is in five years?

Jacobson: I hope we are in this beautiful Ed Roberts Campus with a lot of new energetic, dynamic, young disabled people, and that we have lots of scholarships to give away. I hope there is a disability study program in every big university in California with us being paid to run the program.

Bonney: The Ed Roberts Campus is like a conglomerate of disabled-run organizations like DREDF [Disability Rights Education and Defense Fund] and CTP and Ralf's organization, Wheeled Mobility, these groups coming together in one building, one location, correct. Sharing public spaces and maybe sharing staffing for certain things. Do you think that if this comes to pass, that we could get back to a system of shared resources rather than we are now as individual units?

Jacobson: You know what, I believe, in some ways, there was more disabled pride then than we see today. I do hope that the campus will bring back some of that pride. My hope is that the campus will focus on economics. In other words, I'd love to see a coffee house owned by disabled folks. I'd love to see a wheelchair store owned by disabled folks. We talk about how horrible homes are—halfway homes—I'd love to see some halfway homes owned and run by disabled people. We talk about how horrible rehab counselors are. I'd love to see the independent living movement run rehab departments at every level. One thing if you look at it from a purely economic focus, I think the way you change the world is to get control of its economics. That is what I would like to see. One more thing, I do hope, to go back to WID, we are going to get kids involved. One of my biggest commitments is to find kids, high school kids, all kinds of kids, grab them by the hair, and get them involved. Make them work, make them sweat.

Bonney: You mean kids with disabilities in high schools?

Jacobson: Yes.

Neil becomes chair of the Association of Rehabilitation Programs for Disabled Programmers, 1978

Bonney: Let me go back to one thing. While you were head of CTP, there was an Association of Rehabilitation Programs for Disabled Programmers that started up—

Jacobson: I was the first chairman.

Bonney: I know that, and I want to know how that happened!

Jacobson: And you know what, a couple of years ago I went to Canada to give the keynote to that organization.

Bonney: So this organization still exists. What is it?

Jacobson: That was a kick. I told you about the program in Virginia. We were number two. We helped start, I believe, about fifteen more all over the country and Puerto Rico. I believe in 1978 we began an association of all the programs and we got together twice a year to talk about how wonderful we were. I've got to tell you, at the peak, I believe we mounted about forty-five programs all over the country. It was a kick.

Bonney: You said you were the first chair and you wrote the constitution. What was the organization, other than just patting each other on the back [chuckles], what was the constitution? What did you say?

Jacobson: The premise of the association was to help each other with our programs, help with the curriculum, help with new ideas, help with—just keep us young. It was a big kick.

Bonney: How did you get selected as the first chair?

Jacobson: [laughter] That was easy! Once people knew me, they tend to remember who I am. They wanted somebody who was disabled. I don't know. It was natural. It was a kick.

Bonney: Natural?

Jacobson: I really had a good time going over all over the country giving my two cents.

Bonney: How long were you in this organization?

Jacobson: Only a couple of years.

Bonney: You said a couple of years back you went to Canada and gave the keynote. Is it still called the same name? And is it now international because it was in Canada?

Jacobson: Yes.

Bonney: Are there other countries involved?

Jacobson: I believe there are programs in Japan, Puerto Rico, and Canada.

Bonney: Do you know if Joni Breves is a member?

Jacobson: Yes.

Conflicts with the 504 sit-in, 1977

[Interview 4: April 15, 1997] [Tape 7, Side A]

Bonney: Neil, could you tell me what involvement you had with the 504 sit-in in 1977? [2]

Jacobson: Yes. The 504 sit-in was a hard time for me. I had just started the computer program. The computer program was a very competitive program. The business advisory committee was made up of people from Project Industry. I really had a hard time deciding whether to stay in school or go sit in. Where are my priorities? And I decided to stay in school so I did not sit in. I took my students over to the sit-in a couple of times but never stayed there. So that was a hard time.

Bonney: Did you go to any of the rallies?

Jacobson: Yes.

Bonney: What did you see at the rallies? What went on?

Jacobson: That was a long time ago. What I remember, I remember feeling very, very torn. On the one hand, I wanted my students to know what was going on. I wanted them to know that there was a movement. I wanted them to know that they do have to fight for their rights. On the other hand, I really didn't know whether this was the right way of doing it. Do you know what I mean? Like I said, I knew that the people on my business advisory committee—they didn't like it at all. It was a very hard time for me.

Bonney: Did you not participate because of the business advisory committee?

Jacobson: Be careful. I always believe you always take responsibility. But to say that I didn't do it because of the advisory committee—I don't think that's right to say. It was my decision, but part of my reason was because of the business advisory committee.

Bonney: Did you do any of the organizing or pre-sit-in work?

Jacobson: No.

Bonney: Did you attend any meetings?

Jacobson: [laughs] Yes, and I remember being one of the bad guys. One of the guys who kept on saying, "Is there a better way of doing this? Do we really have to sit in? Why don't we have more political clout? Why do we have to stoop this low?" Looking back, I don't know what I would do if it happened now. On the one hand, it was a radical idea to sit in. On the other hand it worked.

Bonney: Did you take part in any of the celebrations on April 30 when they all came out of the building?

Jacobson: No. I definitely remember that day. I remember feeling very torn. On the one hand, these are all my friends, these are all my colleagues, this is my roommate, and they did a good job. And I wasn't there. It was hard.

---

[2] The month-long sit-in in April 1977 at the Federal Building in San Francisco was part of a nationwide effort to force the secretary of Health, Education, and Welfare to implement Section 504 of the Rehabilitation Act of 1973. Section 504 contained the most significant disability rights legislation prior to the Americans with Disabilities Act of 1990.

Bonney: Have you been involved in any other political events in the disability movement in the last twenty years? Any sit-ins or demonstrations?

Jacobson: I find your question very interesting. First, you asked me if I was involved in any political activity and then you asked me if I was involved with any sit-in—like it was the same thing. I find that interesting. I think everything is political. I think everything we do is political. From that sense, I do believe I've been very political. Have I sat in—no.

Bonney: Or demonstrated, or marched?

Jacobson: No.

President Clinton appoints Neil vice chair of the President's Committee on Employment of People With Disabilities, 1993

Bonney: You are part of the President's Committee on Employment of People With Disabilities—right?

Jacobson: Yes.

Bonney: How did you get involved with that after you were boycotting it in the 1970s and now you are its vice chair?

Jacobson: That I can answer. One of my personal goals is to become involved in a national agency and to learn how to be a professional volunteer, if you will. We spoke about this a little bit last week. The idea that I really believe that disabled people should be professional. We are not as professional as we need to be. I am not using the word professional correctly. If you could help me, I wouldn't mind it. I said that I really wanted to see what it would be like to be on a national agency. What it was like to be on the other side of the table. That's why I really wanted to be the vice chair of the President's Committee. I really wanted to see life from the other side of the table. I've got to tell you I am happy I did. I'm still not excited about the President's Committee. I don't think they do a lot of good work. But I have to tell you that I am learning a lot. I'm learning a lot about how to run a governmental agency. I'm learning a lot about how professional volunteers work. I am learning a lot from Tony Coelho. Tony. Tony is a wonderful guy. Tony is the first professional politician that I can say I know. It's fascinating for me to see life from his side.

Bonney: So what is it like from the other side of the table? What kind of things do you get faced with?

Jacobson: I can tell you two things that I've learned in the last couple of years from being on the other side of the table. One thing is, business people—I'm amazed about how much they need to know—basic stuff. Business people need to hear basic stuff, like disabled people do work. Disabled people do get around. Stuff that we take for granted—of course. Being on the other side, like I said I am amazed how much non-disabled people need basic, basic information. That is number one. Number two, is I am amazed at how much money people have and how easy it is to ask for money.

Bonney: You mean the President's Committee asking for money?

Jacobson: Yes. Yes. Being on the outside, I think, and now I'm talking about all my colleagues, I know I was always intimidated by CEOs or presidents. I thought they were bigger than I was. [laughs]

Bonney: You are one! [laughs]

Jacobson: Being on the other side of the table, I think that is what I learned, they are just as weird as we are. The one thing is, I really think I learned a lot of things being on the President's Committee. I'm still not impressed with what they do.

Bonney: What do they do? What stuff do they work on?

Jacobson: What do they do—that is a goddam good question. [chuckles] If I had to summarize I would say what they do well is PR—public relations. What they do well is making the public—the everyday, non-disabled public—aware. That sounds so corny but that's what I think they do well. I think in that area they do okay. I'm not sure that in 1997 we need a big federal agency to do that, but that is what they do.

Bonney: You used to attend the meetings in the early seventies because we talked about that. Has the focus of the committee shifted or changed over the years? Do you see differences?

Jacobson: To be very honest, no. [chuckles] Well, there are probably more disabled people involved; but, then again, if you start out with zero, it is not too hard to get more disabled people involved. They do have more disabled people involved. They are talking about more contemporary stuff like minority, like small business for disabled people. But I would say that if you look at the whole committee, I would say no. I would say they were always there as a PR mechanism, and they are still a PR mechanism. It could be that the public still needs that kind of PR.

Bonney: As a federal agency, do you think that it works internally within the government with other agencies, the cabinet, the presidency, at that level to heighten awareness of disability?

Jacobson: Yes. For example, Tony Coelho does have access to the President [William Jefferson Clinton]. I do believe that the President has received a lot of disability awareness because of Tony. The Department of Defense has a whole program for disabled kids

during the summer because of the President's Committee. So I would say yes. I would say yes.

Bonney: Do you go to board meetings?

Jacobson: Yes.

Bonney: What is a typical board meeting agenda? What comes up on the agenda that you all talk about?

Jacobson: We have seven subcommittees and each month it is headed by a volunteer. So the board meeting is basically a time for the subcommittees to give their report. Like I said, I think it is a time for them to come together and feel good about what they do. If you're waiting for them to change the world, don't hold your breath.

Bonney: Do you chair a subcommittee?

Jacobson: I am the head of the operating task force. I get together all the subcommittee chairs once a month by phone and we are supposed to make sure that they stay on target and do a good job. Most of the time they do a lot of b.s.—a lot of good b.s.—but a lot of b.s. For a couple of years it really bothered me: but I think the people there need—they get something out of it.

Bonney: Tell me how did you get appointed to the President's Committee?

Jacobson: Judy Heumann.

Bonney: Oh, Judy Heumann. So how did she get you on the President's Committee?

Jacobson: She gave my name to the White House. The White House did a check—no more skeletons in my closet—I don't have too many skeletons in my closet so that is how I got on.

Bonney: So who appointed you?

Jacobson: President Clinton.

Bonney: Clinton. So you've been on since when?

Jacobson: 1993.

Future trends in the civil rights movement for people with disabilities

Bonney: Neil, what do you see as the future of the civil rights movement for people with disabilities? Where will it take us? Where are we going?

Jacobson: We spoke about this last week. I really believe that until we begin to focus on economic development, I think our movement might be stuck. I believe that in the next ten years or fifteen years we have to worry about our own economics. We have to take back—no, we never had it—we have to take control over our own finances. We have to focus on our own businesses. I think the era of blaming the non-disabled white men has come to an end. I think if we don't like rehab, for example, it is our responsibility to have our people take over rehab, take over rehab in schools, in universities and then in the government. If we don't like nursing homes or halfway homes, I think we have to not fight against but take control over them. That's just my opinion.

[Tape 7, Side B]

Jacobson: That is number one, economics. Number two, I think is schools for disabled kids. When I grew up, I thought all the problems would go away if it wasn't segregated. And I was wrong. How about that? I don't know what the answer is, but schools are a major, major problem.

Bonney: What do you see as the problems?

Jacobson: I believe that disabled kids are not growing up to be alive. They are growing up, most of them are without "uumph." I don't see the "uumph."

Bonney: "Uumph?" That will be good to spell!

Jacobson: I don't see the glow in their eyes. I worry about that. That is number two.

Number three, believe it or not is art. I think we really need to do more in the whole area of art and culture.

Bonney: You think there needs to be more disabled artists doing paintings around disability or dance artists, et cetera? Out there, in the public, doing their thing?

Jacobson: Exactly.

Bonney: Let's go back to the schools for a minute. You're talking elementary, secondary, college—I'm assuming you are talking the range. What do you think that elementary and secondary schools should be doing?

Jacobson: I think we have to learn how to balance segregation with integration. I think disabled kids do need disabled peers. A lot of them don't get that now. I think disabled kids lose their identity if they are isolated from other disabled kids. Disabled kids need mentors. Disabled kids have got to grow up knowing that they have to be alive. They have to learn that they have real responsibility. Do you follow me?

Bonney: What do you think about the issues, right now, around SSI that when a child becomes eighteen years old they become eligible to go on SSI and SSDI and that when they go on that we are perpetuating the cycle of dependency on welfare? We are not giving young people with disabilities the opportunities to go to school and grow and to get jobs. What are your feelings about this? Should we give people support services at eighteen?

Jacobson: If they work for it. Again, I don't want to sound too Republican. But I believe that everybody, no matter what their disability, needs to work. There is no free lunch. If a kid goes to school, or if a kid works, or if a kid does something meaningful and if the kid needs more money or more attendant care, or more health care, I think that is wonderful. I think that is great. But, to allow a kid to not work, allow a kid not to work, is not fair to the kid. I really believe that. How about that?

Neil starts climbing the Wells Fargo corporate ladder, 1979

Bonney: Speaking about work, tell me how you got your job at Wells Fargo. How did that evolve?

Jacobson: How the hell did you get from—I thought we spoke about that a couple weeks ago. I was with the computer program for four years telling the students how wonderful it was to work out there in the real world. How wonderful it was to get up at five in the morning and come home at ten at night. How wonderful it was to do all that. I felt the need to get out there and find out for myself. I had an assistant working for me in the Computer Training Program named Terry Davis. Terry worked for me about three and a half years. And then she went to work in the personnel department of Wells Fargo. When I decided it was time to find out what it was really like, I called Terry and Terry got me an interview. Here I am eighteen years later.

Bonney: Have you been with Wells Fargo eighteen years?

Jacobson: Yes, eighteen years.

Bonney: Now, you didn't start out as a vice president. Did you? [chuckles] How did you get to be vice president?

Jacobson: It's not hard. It's not hard. I started out as a programmer. I've got to tell you that working for big business blew my mind. A lot of normal people work there. Normal people are so boring. [laughter] Believe it or not, I am serious about that. I always wanted to work in normal, big business. I always had this grand idea about how smart normal people are, and how marvelous they are, and how energetic they are. I was amazed at how normal, normal people are. I found that if you had any motivation, at all, if you had any spark, at all—it doesn't matter what the hell you look like—you can do whatever you want. I really believe that. I still believe that today. How about that?

Bonney: Were there any barriers that came up against getting to where you are now? We talk a lot about women breaking through a glass ceiling. Was there a glass ceiling for someone with a disability at Wells Fargo?

Jacobson: Yes and no. I had this wonderful idea of becoming a manager because that is how you climb the ladder. A couple of years went by and I wanted to climb the ladder. My immediate thought was, "Aha, aha, I can't climb the ladder because the ladder isn't accessible. I can't climb the ladder because I don't play cards." Boy, I got so angry, I got so depressed, I got so mad, and then I found out that I stink as a manager. I stink. I am a geek. I am a computer geek. I mean that. If you have a technical problem, I can work with you forty hours nonstop. If you have a headache and you want to talk to me about your problems, it doesn't turn me on. What I found is that has nothing to do with my physical disability. That is who I am. I am a geek. One other thing is that you have to be very careful about what is disability-related and what is not.

Bonney: If you couldn't climb the ladder as a manager to get to the top, what did you do to get there?

Jacobson: I stayed being a geek. I climbed the technical ladder. I really believe it doesn't matter what ladder you climb if, number one, you are happy and number two, you keep on climbing.

Bonney: Would you have been happy remaining a programmer? A lower level geek?

Jacobson: No. No. No.

Bonney: So you needed to climb?

Jacobson: Yes, I am a horrible programmer. [laughs]

Bonney: A what programmer?

Jacobson: A horrible programmer. [laughs]

Bonney: Horrible programmer? You stink as a manager and you're a horrible programmer. Why are you still there? [laughter]

Jacobson: I am a great designer. I could see a whole system in my head. That's what I do. I love designing whole big systems. But then somebody else has got to do the real work.

Bonney: When did you become vice president?

Jacobson: 1989.

Bonney: So you were there twelve years before you became vice president?

Jacobson: Ten years, April 9, 1979. Before I retire, I would like to be a senior vice president. Today, there are no senior vice presidents who don't manage. But there will be. [laughs]

Bonney: So you are still climbing the ladder. Great. Sometime in this period when you were working for Wells Fargo, you took a leave or something and went to WCIL.

Jacobson: The Westside Center for Independent Living.

Bonney: How did that happen?

Jacobson: I did that for one year. That was the worst year in my whole life. The good thing about having a really horrible year is that you have something to compare all other years to. I hated it. I hated it. I did a horrible job. I didn't know what the hell I was doing. I was the executive director. I had forty staff members and I told you about five minutes ago that I stink as a manager. And there I was being a manager. I was horrible. That year, the board of directors fired me four different times.

Bonney: The board fired you four different times and rehired you three times? [laughter]

Jacobson: Looking back, they were right. I did not do a good job. I did not know how to keep them informed. I did not know how to make them feel a part of the agency. I didn't do anything illegal or anything horrible, it just was that I didn't know how to keep people informed. You know what I mean?

Bonney: Did you leave Wells Fargo permanently to go to this job?

Jacobson: No. They gave me a one-year leave of absence. The day before I got fired the fourth time, I called my boss at the bank and I said, "I'm coming back on Monday." He said, "Good." But it is very important to know what you are good at and what you're not good at with or without a disability. I'm good at technical stuff. I'm no good at one-to-one. I am a good teacher but as far as managing, that's not my strength.

Bonney: Did you go to Los Angeles with the idea that this might be a permanent career move if it worked out?

Jacobson: I hesitate because I did ask for a year leave of absence. So, I think, in the back of my mind, I knew I stunk.

Bonney: So you went back to Wells Fargo after that year. When you were in Los Angeles, did you work with Brenda Premo?

Jacobson: [laughs] Yes.

Bonney: Was she at the center?

Jacobson: No. She was the director of another CIL about forty miles away. We had our encounters.

Bonney: And how are you today? Are the two of you friends?

Jacobson: Yes, we are. I am happy I am working for the bank and I'm happy she's not! [laughter]

Bonney: Is that all I am going to get out of you about Brenda Premo?

Jacobson: I've got to say this. She was a lot more political than I was. She knew her way around much better than I did. I give her my high regard for her political ability.

Adoption of son, David, 1987

Bonney: Neil, would you tell me a little bit about your son, David? How did he come into your life?

Jacobson: I told you I was supposed to go to an institution when I was a kid. Right after that, one of my goals was to adopt a disabled kid. I always, always, always wanted to adopt a disabled kid. When we got together on our second date I told Denise one of my goals was to adopt a disabled kid. We got married and we tried to have our own. We had fun trying but it didn't work out. We decided to adopt a kid. Then, Denise got a phone call from a friend of Judy Heumann. The friend said, "There is a baby who is six weeks old who was supposed to be adopted by another couple, but the kid may have cerebral palsy and the other couple got scared." They were looking for another home for the baby. The woman told Denise that the baby was born on my birthday. When I heard that, it was like, "That is it. This is our kid." Denise was a little more hesitant. But she flew back to see what was going on. While Denise was coming off the plane, a woman came on the plane and put this beautiful baby right in Denise's arms.

[Tape 8, Side A]

Bonney: So as Denise was getting off the plane—

Jacobson: This woman put this beautiful baby on her lap. The baby looked up to her with these incredible blue eyes. And Denise knew right then and there that's our baby. David came home about four weeks later. I have got to tell you, in my whole life, that was the most wonderful, wonderful experience. I can't tell you how wonderful it was to hold the baby. For that little baby to look up to you and smile. It was a kick. One thing I've got to tell you, whenever I was home I had to diaper him. I don't know why but he always wanted me to diaper him. It took about ten minutes compared to what nondisabled guys could do in about ten seconds. But what I figured out was I'm Daddy and that's what David needed. I've got to tell you it was the most wonderful experience. We talk about how disability is okay and all, life is okay, but a baby really makes it real. When David was hungry, he didn't ask if I was tired, he didn't ask if I can feed him, he didn't ask how I felt. All he did was cry. All he did was demand food. And that was such a kick to have another human being want you. Not because of your disability, not because of your degree, but because you are Daddy and that's what daddies do. I love that.

Bonney: That is still going on today, I assume.

Jacobson: Yes.

Bonney: On a slightly different level.

Jacobson: Yes. David is ten years old now, and he is always, always on the go. I don't know how in hell he does it, but he's always going. When he is awake, he's always going. And I'm still Daddy. I'm still the guy he comes to for whatever he needs or whatever he wants. Sometimes I get tired, and sometimes he gets cranky, and sometimes I yell, and sometimes he cries. But always, always, he knows I am Daddy, and I know he's my son.

Bonney: What about his disability?

Jacobson: He doesn't have cerebral palsy. I believe he did that to come to California. I've got to tell you when David was one year old, he started to walk and four days later he was running. Not bad! That was a real kick. After all those years of learning how to walk, I told you about that, this little guy walked wobbly for four days and then he ran! That was a real eye-opener.

Bonney: When did you marry Denise?

Jacobson: 1983.

Bonney: And David came into your life in 1987?

Jacobson: Yes. David was born December 19, 1986, and he came home March 20, 1987, at 7:48 p.m. from TWA. So now you know where babies come from! [laughter]

Bonney: Well, Neil, this has been wonderful. I want to thank you very much for allowing me to interview you. I think I learned a lot from you and I think your tape and transcripts are going to be interesting to a lot of people.

Disability Rights and Independent Living Movement Oral History Project

Scott Luebking

Cofounder of the Computer Training Project; Advocate and Innovator in Disability and Computer Technology

Interviews conducted by
Mary Lou Breslin
in 1999-2000

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

Foreword

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

Copyright and Use Restrictions

All uses of this manuscript are covered by a legal agreement between The Regents of the University of California and Scott Luebking, dated August 4, 1999. The manuscript is thereby made available for research purposes. All literary rights in the manuscript, including the right to publish, are reserved to The Bancroft Library of the University of California, Berkeley. No part of the manuscript may be quoted for publication without the written permission of the Director of The Bancroft Library of the University of California, Berkeley.

Requests for permission to quote for publication should be addressed to the Regional Oral History Office, The Bancroft Library, Mail Code 6000, University of California, Berkeley, 94720-6000, and should include identification of the specific passages to be quoted, anticipated use of the passages, and identification of the user.

Citation

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

> Scott Luebking, "Cofounder of the Computer Training Project; Advocate and Innovator in Disability and Computer Technology," an oral history conducted by Mary Lou Breslin in 1999-2000, in *The Computer Training Project in Berkeley, Accessible Technology, and Employment for People with Disabilities*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2004.

Tape Guide

Interview History—Scott Luebking

Scott Luebking was interviewed for the Disability Rights and Independent Living Movement oral history project because he was the cofounder of the Computer Training Project (CTP), which later became the Computer Technologies Program, in Berkeley, California, and because he has brought a strong computer technology background and perspective to his advocacy, teaching, and consulting activities in the disability rights movement.

Born in Palos Park, a suburb of Chicago, Illinois, in 1951, Mr. Luebking attended public high school where he excelled in science and mathematics and developed an interest in theater and psychology. After becoming disabled in a diving accident in 1970 between his junior and senior years, Mr. Luebking returned to Knox College in Illinois where he had been studying mathematics, psychology and computer science. He completed his undergraduate degree and came to Berkeley, California, in 1973 to attend graduate school in computer science at the University of California. While a graduate student, Mr. Luebking lived in the Cowell Hospital Residence Program until 1974. An observer of the nascent Berkeley Center for Independent Living, he became involved in various campus and community activities including serving as a speaker for the sexuality and disability program at the University of California, San Francisco. In 1974 he cofounded, with Neil Jacobson, the groundbreaking Computer Training Project with support from the California Department of Rehabilitation. CTP provides computer programming training for people with disabilities that prepares them for jobs with businesses in the San Francisco Bay Area. The program was unique because instruction was provided by individuals with disabilities who, along with progressive staff, fostered and encouraged the values and perspectives of independent living. Mr. Luebking worked with CTP until 1976.

After founding and working with CTP, he went on to work as a computer scientist for UC Berkeley until 1983 and served on the board of directors of the Center for Independent Living in Berkeley during 1981 and 1982. In the late 1980s and early 1990s, he worked as a computer engineer in private industry. During this period he continued to work on discreet projects within the disability community. These included helping to establish Berkeley's first emergency attendant service and working with City of Berkeley officials to secure passage of a ballot finance measure that established permanent funding for these services. Subsequently, Mr. Luebking established an Internet mailing list that is widely used by the northern California disability community to share information on various disability topics, consulted and taught at UC Berkeley's School of Optometry, mentored engineering students, advocated for access in medical services, and worked for accessible voting equipment.

Mr. Luebking's interview took place in four sessions beginning in August, 1999, and ending in November, 2002. Each interview took place at the interviewer's home in Berkeley, California. While Mr. Luebking initially was reluctant to be interviewed, he eventually agreed because he understood the value of recording his recollections about the formation of CTP, the formative years of the disability movement in Berkeley, and the role of a technology expert in advancing the goals of the movement. He spoke thoughtfully and carefully during the interviews. The interviewer frequently provided food as an incentive to continue with the interview. The interviewer was a friend and colleague of Mr. Luebking. The interviews were transcribed and lightly edited by the Regional Oral History Office and sent to Mr. Luebking for his review. Mr. Luebking made no changes to the transcript.

Mary Lou Breslin
Interviewer
May 2004

I. Childhood, Family, Early Interests, and College

Childhood in Palos Park

[Interview 1: August 12, 1999] [Tape 1, Side A][3]

Breslin: Scott, tell us a little bit about growing up in Chicago and your family there.

Luebking: I actually grew up in the suburbs of Chicago and grew up more in a rural area which also is a combination of farms, very wealthy families, and artists, so there are interesting combinations there.

Breslin: What was the name of the area?

Luebking: It's place called Palos Park.

---

[3] A guide to the tapes can be found following the table of contents.

Breslin: Is it north?

Luebking: Southwest.

Breslin: Okay, I've got it located in my mind now. And your family? What was your family up to in Chicago when you were a kid?

Luebking: Basically, a middle-class family. My father worked with sound engineering, and my mother worked from—she has a couple of interests. One is doing marketing research and also worked as an astrologist.

Breslin: And you were born there in what year was it?

Luebking: I was born in Chicago in '51, and they moved to Palos when I think I was about two or three or something like that.

— 68 —

Breslin: And your brothers and sisters?

Luebking: I have one sister.

Breslin: And is she older or younger?

Luebking: Eighteen months younger.

Breslin: You went to public high school in Chicago? Or in Palos?

Luebking: Yes, public.

Puppetry and tutoring

Breslin: Any particular areas of interest as a teenager?

Luebking: I had diverse interests. When I was in junior high I got active in puppetry and found out that I had a knack, so I did protege work at Kunzol in Chicago. It was a special theater that did grand opera using puppets. That's where I got some of my theatrical background.

Breslin: Really? That's fascinating. I didn't know that.

Luebking: Yes.

Breslin: That's great.

Luebking: So I learned a lot about costuming and also was very interested in special effects. My favorite show that I worked with was *Kismet*, where we had flying horses that took off on the stage over the audience, and had genies that appeared and these wonderful puppets that could do a dance. It was one of my favorite shows.

Breslin: Fantastic production. What was your assignment?

Luebking: I just proteged, so I got the go-fer stuff in a lot of things and worked with choruses and did costumes. The Wazir had a beautiful outfit with material that was five hundred dollars a yard in the sixties. I got a chance to work on that.

Breslin: And that's a character isn't it—the Wazir?

Luebking: Yes. It's like the king.

Breslin: Ah.

Luebking: I was very fortunate to have been given that opportunity for two years.

Breslin: That's absolutely wonderful. Were you involved in theater, actually, in your high school, too?

Luebking: Well, as a result of that—well, actually, my father, because of his own background—he worked with sound for the local Village Players—because the background came from lighting and sound from Kunzol. Then I started doing work with theater my freshman year in high school. Up to that point, I had very little interaction with the school except to go to class, but nothing afterwards; then afterwards they found I could do theater stuff, and I started getting involved with all sorts of activities.

My background started playing off into organizational aspects and I found that I was interested in teaching and sharing information, and that's how I got involved with working with emotionally disturbed children. There had been a boy that had had a psychotic episode, from school, who wanted to come back to school but needed tutoring. They wanted him to work with a male in case something went wrong.

Breslin: As a mentor?

Luebking: Well, to help him get caught up in being behind classes. I was in charge of the tutoring program for the Future Teachers of America, and then I developed a reputation for being able to work with emotionally disturbed. So one of the students I worked with was going to go to camp and told the camp director about me, and so that's how I ended up at the camp where I got my injury.

Breslin: I see. Oh, this was in the cards somehow, it seems like.

Luebking: My family used to be a lot into water skiing, and so we used to teach people to water ski, and so the camp where my skills—I worked with emotional disturbed, but also I could teach water skiing, because they were very interested in that.

Breslin: Oh, that's great. That's wonderful. You were in your mid-teens—fifteen, sixteen—when you were involved in both of these activities?

Luebking: Well, I started with the puppetry when I was in about sixth grade, sixth or seventh grade, because we actually—there was a group called Co-Marionette, which were pretty nationally known, but they happened to be—lived in Palos because it has an unusual combination of artists and rich people.

Breslin: That's a great combination, by the way.

Luebking: Yes. And so my mom—I talked about my interest in puppetry and was able through the social network to get to the Co-Marionettes, and they exposed me to the ways of building puppets, and then I built clowns. My first puppet was a clown that blew balloons that floated off the stage. I was interested in not just straightforward but interesting technological problems, like having a puppet that expanded. Then I had a group of talking flowers, so I had a group of flowers that were gossips. I did another one that was a ghost ballet, with handkerchiefs and transformers.

Breslin: How old were you when you were doing this?

— 70 —

Luebking: Seventh grade.

Breslin: Oh, God!

Luebking: And with the Cos [Co-Marionettes] I would spend the summers working with them as they went to Chautauqua Grounds and things like that. They did elephants on stage. They just did a lot of interesting things. But they were more into the handcrafted wood type of things, and I was more into interesting illusions—they opened the door for me to get to Kunzol.

Breslin: That's really fascinating.

Luebking: I don't talk to people about a lot of this stuff.

Computer science, math, and music; growth period of the late sixties

Breslin: That's so interesting. What were you thinking about then in terms of what you might do later in life? Were you imagining making a career out of this?

Luebking: It's funny, but I also seemed to have a knack for math and science at that point. I liked the logic. I really liked the ability to analyze. What I found interesting about the puppetry was that I was able to look at physical problems and by analysis to come up with something that was artistic, and there was a blend for me.

Breslin: This was a little early in the days of computer science, I assume.

Luebking: Right. I really didn't get involved with computers until my freshman year in college. I was invited to be in a special program my first year, where they wanted to work with teaching math, teaching calculus with computers, as an experimental program at that point. Because I had studied calculus. I had shown some aptitude in high school for that, so in the college they were kind of looking for some unusual people.

Breslin: Where did you go to college?

Luebking: I went to a place called Knox [College].

Breslin: And where is that?

Luebking: In Galesberg, Illinois. So when I first starting working with computers, it just seemed to fit. It just worked. I was also studying music for the first time, and I ended up, as my final project for my music class, writing a program that composed music.

Breslin: When was this? What year was this?

Luebking: 1969, or '70, actually.

Breslin: That's pretty rudimentary computer technology at that stage.

— 71 —

Luebking: It depends on what you mean by rudimentary.

Breslin: That's right. What was available at the college level for a student in your situation? What was the kind of equipment you used?

Luebking: We used an IBM 1130, but you had to do cards and all that type of stuff, so it was pretty primitive that way.

Breslin: The input process was primitive.

Luebking: Yes. And then that was, like, the fall of '69, but as I started doing this—well, what happened was I made a mistake. When the first programs I ever wrote in Fortran—there's a thing called carriage control—I didn't know about having to put the first carriage control. I was writing up some number sequence for the class and it turned out that when the number sequence reached 1000, then the number one was being interpreted as a carriage control, which meant it skipped a page. I was getting thousands of answers, but one per page. And when this happened, the director of the computer center happened to be near the computer and got very upset that it wasted so much paper, and so he kind of tracked me down. He understood what was happening—but this was, like, my second program. He kind of kept his eye on me, waiting for my next mistake in the computer center. Then, after a while, he saw that I seemed to be actually doing pretty good. By the second quarter, he asked me if I'd be willing to join the staff as a freshman for the computer center.

Breslin: Really?

Luebking: Which was kind of really weird because I hadn't taken any computer courses, except for this little math course.

Breslin: Let me just back up a minute and ask you about this music interest. Were you interested in performing?

Luebking: I'm not very auditorially oriented; I'm very visually oriented. But I like musicals, that type of thing. But I also came from a family where you expanded your horizons. You'd try to do things that may not fit in with what you've done before. So music was that for me.

Breslin: This was a new area of exploration for you.

Luebking: Yes.

Breslin: So was it a challenge? Was it interesting?

Luebking: Well, I was very lucky that the music appreciation course I was taking, the instructor liked to be creative and would support my willingness to look at computers and music. In fact, we talked about my second quarter and my third quarter—we came up with the idea of my doing an independent study, under him, doing computer-composed music—like taking off from the first quarter.

But the problem I ran into—I can't play music. And so, with the first quarter I had to translate the numbers into musical notation so the music department could play it back for me, and my third quarter I just got really tired of doing this all the time, so I figured out how to program the computer to write the music out for me, which is how I got into computer graphics.

Breslin: I see. Very early on.

Luebking: Yes, it was more out of laziness because I knew I could translate numbers into notation.

Breslin: Out of necessity.

Luebking: Yes. But that fit into my math background of using the mathematics to represent the notation.

Breslin: Fascinating. You know, this was historically—

Luebking: Seventy?

Breslin: Right, late sixties, early '70, a really volatile period historically in the U.S. Were you participating in or having any relationship to any of the political activities that were going on during that period as a high school and college student?

Luebking: I think the thing that I found very interesting was a period of change in terms of people growing. For me, a very central theme is to—which is one of the reasons why I'm doing this thing, is to realize I have a limitation, so I try to expand past that—

Breslin: You say "this thing." You mean allowing us to—

Luebking: Yes!

Breslin: —capture your oral history?

Luebking: Yes.

Breslin: All right.

Luebking: But to see people expand and grow, and I really—I found the women's movement very interesting. I didn't quite understand it because I didn't understand why women would be trapped and limited. I think part of that was because just the way my mother was being more dynamic and out and challenging and stuff, and my sister is the same way. So I was a little bit surprised the women had to do that but, again, it was because I was more naive.

Breslin: Well, your family experience doesn't support what was going on in the rest of the world.

Luebking: Yes, it was different. And I think there was also a difference because I didn't interact with women in the same way that the guys did. I didn't go through that differentiation. My identity wasn't based on girls. It was just based on interacting with the world. And also because when I was very young, I didn't really associate with people that much. I felt uncomfortable with them. So I didn't pick up a lot of male experiences from that because I didn't hang out with the boys and all that, and I didn't have really—people baffled me. I didn't understand them.

Breslin: Gender notwithstanding, people baffled you.

Luebking: Yes. There were things that I saw that just didn't make sense, just intuitively, spiritually. A lot of things, the way people treated each other was very surprising to me. So this male, boyish, put-down hierarchy, status-type of thing—I didn't quite see what the purpose of it was, rather than "Well, let's just talk stuff out." It didn't seem to make sense to me. And I didn't see anything wrong with crying—because I was very sensitive about animals.

I remember one time just I was [inaudible], and I killed a small rabbit because I didn't realize they were underneath [inaudible]. It just really bothered me. For a couple of days, I just felt extremely bad. I remember taking carrots out to the mother rabbit. But I didn't feel bad about feeling bad. It was just that I didn't—my father was rather upset that I was disturbed about the whole thing, because it was a male thing. It just didn't feel right. And so all the guys in the neighborhood—I just couldn't understand what they were trying to do, like torturing animals and things like that. Just male things.

An independent thinker

Breslin: Were there any influences around you that helped foster that sensibility, or do you think you just sort of came with it out of the box? Or both?

Luebking: [pauses] I don't know. It just seemed natural to me. I think what may have been different was somehow this fostering of the independent thinking, that it was okay to think differently from people.

Breslin: Nobody told you that, though. You figured that out by yourself?

Luebking: I think there was still—there was an unusual group of people in that family. We had friends who were mediums. We had a consulting guru [Quiundanda?]. So I was exposed to different ways of viewing.

Breslin: Was your family involved in these activities—

Luebking: Because of my mother, basically.

Breslin: Right. But was this a lifetime interest of hers, or was this in response to the exploration of the sixties?

Luebking: No, she was going to Northwestern and got exposed to astrology. She first thought it was bunk and she didn't believe it, but the more she got into it, the more it seemed to make some sense. Her family was from Lithuania or Eastern Europe, so I think that there's a sense of mysticism that may have come into play as being acceptable also.

Breslin: Is she Lithuanian?

Luebking: Yes.

Breslin: And how about your father?

Luebking: German, American-German.

Breslin: So their interests—it was possible, I think, for them to pursue those interests in the sixties with much more freedom of expression than they might have been able to in earlier decades.

Luebking: Well, see, the area was actually rather conservative because of the money.

Breslin: Geographic area.

Luebking: Yes. We had neighbors who were millionaires. We had neighbors who would build an indoor swimming pools and had strange houses and all this stuff, so there was a wide gap. [Barry] Goldwater was very popular. I was always more on the liberal edge. There were things that—for me it was going back to people somehow as being important. I didn't understand them, but I understood them at a deeper level than they understood themselves, which is why I was able to work with the emotionally disturbed. Somehow I could see through the over aspects and see the deeper aspects. Sometimes when I work with the emotionally disturbed, there were times they would act out and end up with bloody noses and things like that. You kind of had to see the deeper part of them. Am I making sense?

Breslin: You're making plenty of sense. What's interesting to me is that you came to these insights without having been mentored to them by anybody. Is that right?

Luebking: It just seemed obvious somehow. I don't know how to explain it. I remember one time getting in trouble with the neighborhood boys because they were going to torture some fish, and I rescued the fish and let them go in a nearby pond because it just seemed right.

Breslin: That was the right thing to do?

Luebking: And the neighborhood was very upset with me. I mean, I don't know how to explain it; I just didn't understand why they should be sacrificed to the boys. What did the boys get out of this? Not a respect for life or something like that.

Breslin: How did your family react to those sensibilities in you?

Luebking: Well, my father was quite baffled by me. We had no interaction, and I have not really talked to him since October '73.

Breslin: You haven't spoken to him since then?

Luebking: No. He introduced me to his new wife when my sister was married in '76, but it was, like, two sentences.

— 75 —

Breslin: That's a long time to be estranged. Or do you consider yourself estranged? Maybe you don't.

Luebking: I don't think about it.

Breslin: Your mother is still living?

Luebking: Yes.

Breslin: Are you still in touch with her?

Luebking: Yes.

Core identity and sexual orientation

Breslin: You said something to me a while ago about core identity formation and how you felt that yours was pretty much formed up when you were in your early, mid-teens.

Luebking: I think before there were certain key things, just things that I just seemed to believe or just seemed to know.

Breslin: What are those things? Or what are the three or four or five key aspects of those?

Luebking: I'm not sure they translate into words that well. Words are actually uncomfortable for me. I think in pictures, and I think in images. And so sometimes it's hard to express this stuff. It's just a central sense. I think probably because I very rarely talk about this so I don't have the experience of taking the words to apply, which is a belief about people being connected, and that what affects one person affects other people. It's hard. Like ecology somehow, but applied to a deeper level of people.

Breslin: The reason why I asked about the core identity issue is that later, when you experienced disability, you have a viewpoint about its role in your core identity, and I was just interested in having you reflect a little bit on you felt about yourself and your sense of worth at that point in your life, before you became disabled.

Luebking: I wasn't always that worried about people's view of me in certain ways. I think I wanted to come off as being competent and being good at what I did. I think that was important. But I didn't feel that it was as important to fit into social things. I sometimes confused people because they'd want to put me in one box or another box or something, because I could be rather logical and analytic but I could be very artistic and intuitive, and they're not different for me; they're the same. I do well with math and sciences courses, but also I could build a sculpture and things like that.

So I didn't have to fit into what people perceived, so when I realized that I was gay, it wasn't that much of a problem. I wasn't worried about how people judged me. I knew not to bring it up with people because of the reaction. Other people are afraid of being judged, and they feel their self-worth would be affected. For me it was more of a tactical

type of thing, that I didn't want to have to deal with the consequences of it; it wasn't important enough for other people to know.

When I became disabled, it was a similar type of thing, that was not core—it was like key to me—there was a part of me on the outside, but it was, like, a central piece.

Breslin: When did you realize you were gay?

Luebking: Junior high, I think.

Breslin: And was that an epiphany or was that a slow process? Or can you recall now?

Luebking: [pauses] Well, I think it was a matter of slowly realizing that I was attracted to watching guys. [pauses] I don't think I really—it just was a slow process. I think I was aware of that, and then when I heard about gay or homosexual, it was like—I hadn't really been active sexually. It was like, oh, okay, maybe this is what's going on.

Breslin: A name for it.

Luebking: Yes.

Breslin: The interest.

Let's pause for just one second.

II. Moving to Berkeley, 1973, Human Sexuality Program, Cofounder of Computer Training Project [CTP]

Pre-UC Berkeley days

[Interview 2: February 28, 2000] [Tape 2, Side A]

Breslin: This is Mary Lou Breslin interviewing Scott Luebking. This is interview number three. It's February 28, 2000. Scott, you had wanted to talk a little bit about some people who were memorable from your pre-UC Berkeley days. Why don't you tell us about them?

Luebking: When I was in college—my freshman year, there were six of us that became friends in a math class. And so after my injury, they really worked hard with the college to get them to let me come back. The first quarter I was back, they were very helpful—I mean just incredibly helpful about making sure I got into cafeterias, and making sure that my needs were met. It was Chris and Carol and Tom and Scott and Susie. I think without them, and without Frank Young, Professor Frank Young, that it would have been much harder—if not impossible for me to have returned to college.

Breslin: And these folks were classmates and friends.

Luebking: Yes.

Breslin: Can you talk a little bit about specific roles that they played that were helpful?

Luebking: I'm not sure how helpful this was, but we were known for practical jokes. And one time we walled up a professor's offices with cans and things like that.

Breslin: Empty cans or full cans?

Luebking: Empty cans. Then another time we worked to get—one of the finals into a *Playboy* and turned that in—and things like that. Very, very progressive. [laughs]

Breslin: [laughs] These were people that you were—that you had made relationships with before you got disabled?

Luebking: Yes.

Breslin: —and basically came back and reestablished those relationships.

Luebking: Well, they were coming up and visiting me in the hospital and all.

Breslin: So what kinds of things did they offer you that made a difference as you came back—

Luebking: Because the place not being totally accessible—they were helping me getting up and down stairs, like for dinners, and running errands, and running interference with the administration, helping make sure I got my laundry done. Things like that.

Breslin: Are these the kinds of things that we would now be using attendants to do?

Luebking: Well, I was still getting used to using attendants. And so part of it was having problems with finding attendants.

Breslin: I see.

Luebking: So they were filling in for that.

Breslin: Have you maintained contact with them?

Luebking: No. We drifted apart when I came out here, and unfortunately I haven't been back for many years at this point.

Breslin: You mentioned Professor Frank Young. What was his role specifically?

Luebking: Well, he was our professor; we met in his class and then we just became friends with him. Afterwards when I returned to college, he was my college advisor before I declared my major, and he was a kind of a radical and was willing to take on the university—or take on the college to make sure I got back.

Breslin: Was he in computer science? Or—

Luebking: Mathematics. My undergraduate work was in math.

Breslin: Anything else you want to say about those folks?

Luebking: I just—as I thought a lot about it, I guess I have been very lucky in a lot of ways with my disability, and I think that they were definitely part of it.

Breslin: Do you remember their last names?

Luebking: Yes. Chris Nichols, Susan Main, Tom Smedinghoff, Carol Plagge, and Scott Drysdale.

— 79 —

Arrival in Berkeley, working with the Human Sexuality Program

Breslin: Okay. So let's come back to Berkeley and talk about your recollections of becoming involved with people with disabilities on or off campus. When did you first have some sense of there being a political movement in the disability community here?

Luebking: Well, originally the reason I came to Berkeley was not so much because of the Berkeley politics as much as in the *Rehabilitation Gazette* out of Illinois?

Breslin: Or St. Louis maybe?

Luebking: Maybe St. Louis. It used to be called Toomey something—

Breslin: *Toomey Gazette*. Right. Yes.

Luebking: Yes, I think that's it. With Ginny—

Breslin: Ginny Laurie. Right.

Luebking: Yes. I ran across that. I'd say that really was a major turning point for me—was reading about the Physically Disabled Students' Program at Berkeley. I think it was my junior year in college—that I think I had a subscription at that point, and I was reading it, and it was like my whole life came together because Berkeley had a very top computer science department and accessibility, and so it's like I wouldn't have to worry about that. So it wasn't so much in terms of politics as much as a less hostile environment for me to be going to grad school in.

When I got to Berkeley [in 1973], I was aware of the political stuff because of reading through *Rehabilitation Gazette* and things like that, and I saw people were spending a lot of time with the political action. I'd say I was more socially involved with the disabled community rather than politically involved. The second month I was here, I went over to the Human Sexuality Program, with Susan Knight and [Dr.] Bob Geiger. They were surprised at how much I had worked through my sexuality related to my disability—and how much I knew. I was surprised that they were surprised, because I felt that there wasn't that much I knew. Then I figured out, well, there wasn't that much more to learn, so that was kind of interesting. Then I started—they had me do the first panel on sexuality and disability with Judy Heumann and Larry Biscamp.

Breslin: Would you just say a little bit about the makeup of this program—the Human Sexuality Program?

Luebking: Actually Susan Knight was working with Bob Geiger on sex and disability issues as part of the Human Sexuality Program. The Human Sexuality Program was a program in the Department of Psychiatry over at UCSF, and then it also involved the National Sex Forum. And so eventually we ended up doing more and more panels and then started doing groups and weekends for the Human Sexuality Program, and it moved from being just general disability stuff—moving from disabled stuff to general sexuality in doing the group work and all—which I think I learned a lot in. I think it also helped me to be less scared about teaching, because if you can talk in front of 500 people about sexuality, you can talk about almost anything. So I think that was good preparation.

Breslin: So your first panel presentation that you were called to do was with Judy and Larry, right?

Luebking: But that was the first one they had.

Breslin: The first one they had *and* the first one you participated in.

Luebking: Right.

Breslin: Who was the audience for that?

Luebking: I can't remember whether it was through the Human Sexuality Program or the National Sex Forum, but one of those. They shared a lot of the same people.

Breslin: I'm just wondering if it was an audience of people with disabilities, or if it was a general audience.

Luebking: No. It was a general audience. I can't quite remember—that's one of the professional audiences, like we did a lot for—oh, as part of continuing education for nurses and doctors and all. One time we had a group for religious figures who were dealing with nuns and priests and masturbation, and it was an interesting weekend.

Breslin: God, I'll bet it was.

Luebking: Yes.

Breslin: So was this sort of the first experience that you had with actually working together with people with disabilities on a somewhat disability related topic?

Luebking: Yes. Really. Because before that when I was on campus, I was the only disabled person.

Breslin: You mean at your previous school.

Luebking: In my college.

Breslin: Your college.

Luebking: I was the first person ever to be permanently in a wheelchair on campus. There were people with disabilities, more minor or invisible. But the funny thing is that I actually went to school with Joe Heumann. Judy Heumann's—

Breslin: Judy's brother?

Luebking: Yes.

Breslin: Did you really? When was that? What was the overlap between you?

Luebking: We were in college. He never mentioned Judy to me.

Breslin: Oh, that's fascinating.

Luebking: So it was very—I knew his wife, the one who became his wife and all. It was actually Judy and I, a couple of other people were in a van, going to the city, I think we were going to do something for UCSF, I can't remember exactly what. And we passed a house with my college colors. I said, "Oh, that's like—those are my college colors." I mentioned that someone had left a racetrack to the school in their will and Judy asked, "Did you go to Knox?" And I said, "Yes." And she said, "Well, did you know Joe Heumann?" I said, "Yes." But it was curious that he never mentioned anything about her.

Breslin: Any insights about why that might have been the case?

Luebking: I have no idea. I mean we weren't close. It was just like, "Hi, how are you?" type of thing.

Breslin: Do you think he was aware of her developing fame and notoriety at that point?

Luebking: Probably to some degree.

Breslin: You mentioned a minute ago that your relationship with the disability community or people with disabilities was more social than in relation to the political activities going on. Do you have a recollection about what those political activities were? Do any particular ones stand out in mind even though you—

Luebking: I was watching the development of CIL and what was going on there. I think for me, I didn't quite know what the independent living movement was, and I didn't quite understand the importance of it, because the things that they were fighting for were things that I took for granted, and so I think it was—because I had already gone through college where there wasn't anyone in a wheelchair, I had to develop the whole thing. That—I knew I could do it. I didn't quite make the grasp of that. But again, I was very limited with my experience with the disabled, because I thought, "This isn't hard, you just do it." I think that might have also been the background I came from, which in a way kind of prepared me for this.

Breslin: Did you have any perception at the time you were—I mean about this, that other people's circumstances might be different based on their economic situation?

Luebking: Well, you see that in rehab. I think there may have been a difference, because again, I was in grad school, and so a lot of my time was focused on studies. Especially since part of my undergraduate work was in math and not in computer science, so I had to make up a lot of information. And so I think that was part of it, but it wasn't—I think for other people when they got involved with a group of disabled—it was like they weren't different, they were similar and so it was more reassuring somehow. So I think that the independent living aspect was useful for that—and my experience was more—since it wasn't really at the core of my identity. It was just more something that had been added on as another layer when I was older, that I didn't have that same sense.

— 82 —

Breslin: And you also being a serious student, which was your primary focus.

Luebking: Yes. Yes.

Breslin: You said that you—

Luebking: But I also wanted to be doing things to help people—that was the way I was raised. And so working with the human sexuality program was something that I felt that I could give back, through—because part of my background's in clinical psych and counseling—so some of that stuff came through in that way. I wouldn't say I was strongly politically active.

Observer of evolution of Center for Independent Living [CIL]

Breslin: You mentioned that you were an observer of the evolution of CIL. Can you say a little bit about what you observed? What were you thinking about as you were in an observer position?

Luebking: I think that they had just started a few months before I got there, so it was still the apartment on Haste Street. I saw them struggling with stuff, and I was more surprised at the mistakes that they made. Some of the things I saw and heard, just didn't make—we were surprised in the approach that was taken.

Breslin: Do you remember what those were?

Luebking: I probably shouldn't say. I was just surprised.

Breslin: Oh, I think everybody has better analytical hindsight than you necessarily do right at the minute when something's going on. It might be helpful to have the benefit of your hindsight.

Luebking: Maybe some of the stuff later on I'll go into—

Breslin: Okay. You observed the formation of the organization from a management perspective or from a funding perspective—

Luebking: Yes.

Breslin: As well as from a—

Luebking: Not officially, just little things I heard.

Breslin: Did you have some sense that it was a good idea—that the organization was a good idea? Or were you—did you think it had a purpose?

Luebking: I definitely think it had a purpose.

— 83 —

Breslin: A useful purpose—

Luebking: Yes, I think it was a useful purpose. I didn't see any reason not to do—but I think the thing that was surprising me more was why it hadn't happened before. It just seemed reasonable—so when people are talking about this being a major thing, and as I learned more about the history, I could see where it was a change. But I still don't understand why it didn't happen before.

Breslin: What are your thoughts about that now?

Luebking: I still don't understand why it didn't happen before.

Breslin: Do you think it could have happened before? But for what—but for leadership, but for the right circumstances coming together? What would have prompted it to happen before it actually did?

Luebking: We weren't real good about analyzing leadership aspects because I think I have a blind spot with that. But I think it was more possibly influenced by my own personal experience, and like what you were saying last time we talked when I mentioned about how I left rehab and went directly back to college. It was like no big thing, this was just logical. And your reaction kind of got me thinking that this is—was not that logical, and so it's that type of thing, that things that seem so obvious aren't obvious to other people.

That's one of the things one of my professors said in college was I had a very clear sense of things. But I think that may have been because in ways, growing up, I didn't interact that much with people. I did but not—so I wasn't quite as influenced, and that has been helpful with clarity of thinking but also less helpful in understanding how people relate to each other. So it was a double-edged sword.

Breslin: You suggested a couple of times that idea of independent living should have come about earlier because it was a logical need.

Luebking: Yes.

Breslin: Were you at the time you were observing sort of the early days of CIL, were you thinking about what the organization was trying to do in relation to the political and economic state of people with disabilities generally?

Luebking: I didn't see it as quite that strong yet. It seemed to be more focused on the local community. Again because it came out of the Disabled Students' Program, and I think it was a way for people to test what they were able to do, and as they learned that they could have more influence locally when they brought it out from local to national. But I think it was still—it took a while for them to get to that point.

Breslin: I think my question has more to do with your observation of the need for that kind of organization or that kind of philosophy, and the fact that it could have been done earlier, or should have been done earlier, or you didn't understand why it hadn't been done earlier. In looking back now and thinking about your observations, were you at the time thinking about what it would have taken to make, sort of move that philosophy forward at an earlier time historically?

Luebking: Since I wasn't disabled before that, I didn't have that great a sense of history and probably from what I understand, one of the reasons why it was successful here at Berkeley was probably the community in terms of the overall community. Also, you had a group of very bright people where the university was a magnet for them, and I also have a suspicion it had something to do with that a lot of the people that were coming through were disabled later on in life, like me. So their view was what they can do so they didn't have to fight through as much what they couldn't do. Again, for me it was like, "Why don't I just go up and go to college?" It was just—that was it.

Meeting John Velton, birth of the Computer Training Project, 1974

Breslin: When did you graduate from Berkeley?

Luebking: I dropped out after my first year.

Breslin: And what happened at that point?

Luebking: Well, I was in theoretical computer science. And I could see where it would be fine but one of the things that really bothered me was like if I die and had come up with a great algorithm, I'm not sure it would have really helped people that much, so there was always this piece of wanting to help people and—but not sure what to do with that—but also needing the intellectual challenge of computers. And so I talked with my advisor—he was a great guy—he was actually a very brilliant theoretician—I mean I really paled in comparison to him.

Breslin: Who was it?

Luebking: His name is Manuel Blum. About three years ago he won the Turing Award. The Turing Award in computer science is like the Nobel Prize—he's a great and wonderful guy. He's been given a number of awards on campus for his teaching and all and he was very supportive when I just—it didn't feel quite right. I wasn't sure what was missing and part of the problem was that the area that I eventually ended up with professionally having to do with a field in computer science called human and computer interaction didn't exist at that point. If it had existed in college or in grad school, I would have definitely stayed on.

My old college advisor, who every summer comes out and contacts me and we go out at dinner or lunch, reminds me how my greatest mistake was not getting my Ph.D. [laughs] I appreciate his reminding me but I say, "At that time they didn't have what I would want to have done." In a way it was kind of a fluke because when I was in college, you could see me in the math department, the computer science department, the theory department, the psychology department, and people had a hard time classifying me, because I would just kind of float between them and what I learned as I got older was that people have more distinct walls between the fields and like someone said—"Well, you can jump from a to d with no problem." I said—"Oh, is that a jump?" Because it was just kind of—all, all blends and that's why—

Breslin: You don't need to stop at b and c and d.

Luebking: It's just—it's a big picture. I don't know how to describe it—it's all part of the overall landscape. Am I making any sense?

Breslin: Yes. So you decided to drop out after a year, and you consulted with your advisor who apparently understood what your concerns were.

Luebking: Yes. He was really—he was very unusual in the department he just had—a warm, teddy bear type. Plus absolutely brilliant. His advisor at MIT—yes, he comes from a very long pedigree of advisors and all, so I was very lucky to have him.

So I was kind of trying to figure out what to do with my life at that point and one time I was in bed up in the hospital—up in the residence program, and I was sick in bed, which very rarely happened to me. I think it had something to do with my wanting to get out of grad school and all, and this guy named John Velton was kind of known for wandering around. He was part of DR [Department of Rehabilitation]. Oh, I realize why I got into the residence program without DR—because I didn't need DR to pay for it.

Breslin: Right. Your insurance company was covering the cost.

Luebking: Yes. Did I tell you that?

Breslin: No. No. But we haven't talked about it actually, but you might want to just say a few words about that.

Luebking: I don't think I want to talk about the insurance company, because I want to keep that part of my life—

Breslin: Okay, that's fine. So John's wandering around the halls—

Luebking: Well, not wandering, but he knew I was into computers and this project that developed in Virginia on—there was a guy who had an accident, a guy who worked for IBM, had an accident and became a quad, went back to work for IBM and was pretty successful. He was—he got the ear of someone—an upper executive about creating a program to teach severely disabled to become programmers. So he set one up in Virginia—I'm trying to remember exactly where it was—but it was a place where—it really reminded me of a warehouse of disabled—where the disabled lived in this institution. It actually was quite depressing.

Breslin: Was it Woodrow Wilson Rehab?

Luebking: I think so. That would have been right.

Breslin: I think that's where it was.

Luebking: Yes. That sounds right. And so John was talking with me and wanting to know what I thought about it. I have mixed feelings about it, because I thought it would be helpful for people and—but I didn't know whether it would be intellectually challenging

enough for me and yet—but I also like to be creative—and here was something new and different. So he kind of just asked me to think about it and all.

Breslin: At this point was he asking you to think about being involved in developing a program? A similar kind of program.

Luebking: Yes. Then he also said it would heighten my background in psychology with a clinical emphasis, and then he kind of went away, and I really didn't think that much about it. I started doing some volunteer work at the CIL, like once a week just doing peer counseling or something like that.

Breslin: What year was this when John—

Luebking: 1974. So I think John must have approached me like April or May or something like that of that year.

Breslin: And were you at that time working as a peer counselor at CIL? Or was that—

Luebking: Volunteer. I think one day a week or so. Because I was looking for things to do, and I didn't quite know where I wanted to be.

Breslin: Did you have any relationship with the Disabled Students' Program during this period?

Luebking: Well, just wheelchair repair, attendant—

Breslin: Services primarily.

Luebking: Primarily services. Hanging out for lunch sometimes. That type of thing.

Breslin: A lot of people have actually talked about hanging out for lunch at DSP during this period, which is—

Luebking: It was pretty common.

Breslin: Yes. And not so central to your interest particularly, but do you have any particular recollection of what that was like?

Luebking: People kept taking turns cooking. The talking in the back—in the parking lot.

Breslin: DSP was still—

Luebking: —on Durant.

Breslin: Yes. On Durant. So John went away, you thought about this notion of training people to be programmers. Did you visit the program—the model program?

Luebking: Eventually, yes.

Breslin: I see. The first information that you got was really through John's perception. Had he visited it at that point?

Luebking: I can't quite remember. I don't think so. But there was a guy from IBM, and he was actually the guy that was going around the country. I can't remember his name. A very nice guy. I believe he was Mormon. Great smile.

Breslin: From here?

Luebking: He was from IBM, but he came out here—he was opening up a lot of doors with the IBM identification.

Working with Neil Jacobson

Breslin: So what happened next?

Luebking: I think it was like in fall that John—I met with Joel—John and Joel.

Breslin: Joel?

Luebking: Neil [Jacobson] might have it in his records—they were talking with me and wanting to know whether I would do it. They wanted to know whether I knew COBOL. I knew they didn't know enough to ask me the right questions. When I was in college, I had written three COBOL programs. The first program was to read a card in and write the card out; the second one was to read a card in, add two numbers, and print it out; and the third one was to search. In all, I had worked with COBOL for four hours, or something like that.

Breslin: Your knowledge base was—there was not a lot of depth in your knowledge base.

Luebking: Very. Yes. It was—I knew I had an ability to acquire languages, so I wasn't too worried about it and then—there's so much other stuff, and I figured—I'll just answer their questions honestly.

Breslin: What were they proposing?

Luebking: To set up a computer training project similar to the one at Woodrow Wilson, but they wanted to make it more—not residence-based, which is what I agreed to. They also were wanting to set up for people who could work from home—when they got jobs. I actually opposed that, which John Velton still laughs at—because I really didn't think that disabled people should be stuck at home working. And then after that I spent most of my working life working from home. [laughs] But I thought that was a part of their lives in terms of everyone has a social life, and so we had some differences that way.

They had a lot of work reaching out to businesses to create the business advisory group. That was very crucial to the success of the program. They wanted to bring in DR. They wanted people in the disabled community. They wanted to bring in the business community, which—again, this was one of those things that should have made sense, but it was radical. I wasn't quite sure why that was, but when I was in college I studied family dynamics, and these things just made sense from a family dynamics point of

view. When I went into rehab, there had been a more team approach towards treatment—where we would work together—so I kind of just came from this tradition of everyone working together. So when this came up, it wasn't surprising to me, but they were rather proud of what they had done and all.

So they wanted a budget. At that point John had been to Neil Jacobson, who had started grad school the year after I did—he was the one who had suggested I get my own advisor. I thought that to make this program successful, I really had to be very clear about where I was going to be at, and what were my skills, my limitations. One of the things I realized being, in some ways, very shy and withdrawn was that there would need to be someone extremely outgoing to deal with the business advisory committee and that really would be very crucial to the forces melding together. I also knew I didn't have that skill and Neil was very outgoing and very bright, and I also thought in a way he might be a better role model for dealing with disability issues.

One reason they approached me was because they really wanted to have a disabled person to be a role model for the others. I'd always been kind of ambivalent about being a role model, because it was like, it just seemed obvious to me for things—and it's like I didn't really have a role model to deal with being disabled, so sometimes I didn't quite understand that role. There's also this piece of not being—Neil's identity was very centrally disabled and very proud of being disabled and I was more casual about it. I thought I would be better at listening to people and being able to allow people to talk about stuff, so I was a little bit better on a one-to-one basis and I thought we made a good combination that way.

We both could be considered to be rather intelligent, but we were intelligent in different ways, so we'd complement each other in that way, plus I could read Neil in ways, which he would find frustrating, and that he's—one of the things that challenged him was that he was used to losing his temper and getting very angry and storming out, and he did that to me one time—and I just blocked his way, and so he learned that he couldn't get angry and storm out. So there was that piece of it.

Karen Topp [Goodwyn] was involved—as a contact with/liaison with rehab, and she was very important. One of the problems that we had with Neil was in ways he was rather naive about many, many things. And we spent many hours talking about things. I can think of a number of times that we closed restaurants—we'd look around—we had like a staff of five people waiting around. [laughs]

Breslin: Waiting for you to leave?

Luebking: Yes. We would be so out of touch with what was going on. For example, Neil didn't want to have disabled people tested. He said disabled people were tested too much. My argument was we only have so many resources, we can only teach so many. And this went on for weeks and weeks. I had problems with John Velton that—John wanted to have Neil involved as assistant or something and John, because he questioned Neil's abilities because of the speech, I suspect, and—

Breslin: Did he say that directly? Or are you intuiting that that was an issue? Or do you recall?

Luebking: It was very clear. I remember they were exactly those words—he was very concerned. A number of times over the years afterwards he told me how right I had been in the choice of Neil. And again—we had some problems where the ways I wasn't comfortable with the business community because it didn't make sense to me, coming from a more academic point of view. Neil just feels great about so many different people, and so it really worked that way. I would sit in the office and send Neil out to deal with the business group.

I think a thing that we had going for us also was creative problem solving that things that were—are now traditions at CTP. Like late Sunday night, when a problem came up, something wasn't working—it did kind of give me some insight into how traditions in churches could have been created [laughs] in—similar late Sunday night discussions about problems.

Breslin: Let me just ask you a question about process here. John approached you originally to take on a leadership role, I assume in developing this program.

Luebking: Yes.

Breslin: And at that stage you, on your own, started looking around for some support from—for some colleagues—for some people to work with.

Luebking: No. Neil and I had been friends at that point.

Breslin: I see. When John approached you, you knew each other. You and Neil knew—

Luebking: Not initially, because Neil wasn't here. But we came back a second time in fall when it looked like they had the business group ready.

Breslin: And Neil had come onto campus at that point?

Luebking: Yes.

Breslin: And you all had gotten to know each other, so you began conversations with Neil about the project and the possibility of his having a role in the project. Is that how it worked?

Luebking: Yes.

Breslin: And were you having group conversations with John and Karen and Neil to—

Luebking: Eventually. Yes.

Breslin: But primarily between the two of you at the beginning?

Luebking: Pretty much. Yes.

Breslin: Okay. So where did things go from there?

Luebking: Well, we had to come up with budgets, so Neil and I had to learn about budgets and all.

— 90 —

Breslin: Both of you?

Luebking: Yes. I looked at it as being a mathematical problem, so it wasn't hard to get the mathematics. Another thing I realized was, I was not good at paperwork. I'm very bad at paperwork, and Neil loved filling out pieces of paper, so we had a good match that way.

Breslin: God—that's perfect.

Luebking: I was a better programmer than he was—in some ways I'm a little more thorough. We had to write an editor for the system we were using, and then we needed access to a computer, so we went to our old grad school advisor who was great—he signed papers so we got access to the university computer under some logic. I can't remember what it was exactly.

So we had—again—just the right people showed up at the right time with the right pieces of information. The business advisory group was very supportive, and I remember Bob Smiley from Fireman's Fund was the first chairman and there was someone from Del Monte that Neil got to know pretty well. Also, at the same time when this was happening, Ed Roberts had been chosen to become director of rehab.

Breslin: This was still late '74, or early '75?

Luebking: Early '74. We were a little bit worried about whether rehab would turn this grant down or what was involved—but when he became designate for the position—as being in charge of rehab, that opened doors for us.

CTP funding

Breslin: Do you think that the—did the project require approval at the state level?

Luebking: Yes. We were going to be state funded.

Breslin: So the regional office—the Oakland office was seeking support at the state level for it. Is that the right administrative structure? Or are they empowered to develop it without explicit approval?

Luebking: John would know this better. I don't know exactly how John got involved, so I don't know—I can't answer that piece.

Breslin: I was just wondering if you had any sense of whether there was opposition.

Luebking: Well, there was opposition.

Breslin: And sort of at what level was there opposition.

Luebking: State level. But I don't think it was overall. I think there was—I think it somehow got involved with office politics—or department politics or something. But I do know that we were definitely concerned about whether it would actually happen until it did, and then we needed to have a funding place for the program and it seemed to make the most sense there. One of the things that we did was we wanted to make sure that the program was separate from CIL, so we wanted to have a separate building, and CIL's handling of money was not as standard as would be expected.

Breslin: Is that why you wanted a separation from the program? Or were there other reasons?

Luebking: We weren't—that was part of it. And it was also we knew them to be—Neil and I thought very differently about some stuff than the rest of CIL did, and we wanted to have our independence that way.

Breslin: Can you say a little bit about what those differences were about?

Luebking: I really don't remember the details, but I think it would have to do with the funding. How money was going to be handled. We didn't want to be under CIL's thumb, but we needed them as fiscal agent.

Breslin: Thumb meaning administrative thumb?

Luebking: Yes. Especially since they didn't know computers, so they wouldn't know what was going to be needed, and a few things like that. In a way, Neil and I complemented each other—that I had a hard time driving people—

Teaching CTP's first class

[Tape 2, Side B]

Luebking: I didn't quite understand this idea of motivation or how to do it. I mean, I knew it from psychology, I knew a variety of things, but I just didn't have preset—Neil was better at that. Neil had a hard time deciding when someone wasn't making it—and so I could do that, and I could go and tell the person.

Breslin: Deliver the bad news.

Luebking: Yes. So again—there were ways we just kept complementing each other. I think that there—making decisions about who to have in the program was challenging that first year. They had come up with some tests, which actually are still used these days that IBM had recommended. I eventually learned that one thing I was good at was getting a sense of who would be a good programmer, who wouldn't be a good programmer. I could never quantify it, it was just—what a lot of people don't realize is that I'm actually a very strong intuitive, and there's things I just sense. I couldn't explain that. I think that kind of drove Neil crazy.

Breslin: Yes. Well, the guy who's advocating for tests also has the intuitive sort of capability to decide whether or not the test results are even valid.

— 92 —

Luebking: For me it was a combination that looked at the test as being a first pass, but yet also there are some people who can't take tests very well. So it's that combination that's really needed. And sometimes there are people who may not do well on tests, but they're motivated enough to move it past that. So it was just a lot of different factors. One of the things we knew was we needed to have the first class be successful. So we were careful that way.

I think one of the problems that we had—I know one of our mistakes that we made was we were coming up with the—what would be covered in at the nine months—and we thought—well, okay, we needed—we knew that logic would be a great beginning of the class. When I first started grad school in computers, I was never taught logic. It was just like, "Oh, well, this makes sense." And Neil was similar, and so we thought, "Okay. One day we'll teach logic." It was like, "Ohhhhh—Okay—maybe we should make it two days just to be on the safe side." The business advisory group says it's still going to be a lot longer. Again we were young, we were cocky, it was like, "Oh, sure. We know this; they're wrong." So we got into teaching it and it was like—

Breslin: Three weeks.

Luebking: Six weeks. [laughs]

Breslin: [laughs]

Luebking: It was an absolute disaster. We had totally blown it. And in a way our lack of experience showed that we just totally misunderstood that. One of the things we had done—we wanted to be creative, so the first homework assignment that I think I gave for over a weekend was to go home [laughs], get a tape recorder—and I gave a problem—I just asked them to do stream of consciousness of how they would approach the problem. So they turned in their tapes and when I went home and listened to the tapes that night it was so—I was so depressed by eleven o'clock that night—it was like—they were thinking of ways of solving problems that made absolutely no sense to me. It was not at all logical and I called Neil up—I said, "I think we're in trouble." I was just, I was so blown away by that, and I thought—"Oh, no maybe"—I kept saying to myself—"Well, maybe it's just because it's their first time, and they weren't used to it or something like that."

What I realized was my lack of experience with people and being—basically going through honors classes—and just—I was not really exposed to a wide range of people, so that poorly prepared me for this. I think I made some—there were other mistakes that we made, but it was just—it was a real shock.

Then we both felt—I remember this Sunday night before the first class, and Neil and I were talking and we kept saying, "We have twenty people's lives in our hands. And we're only like twenty-four, twenty-three." It was really—I think we kind of knew it, but it was like that time was so critical. Like who the hell were we to be doing this. Neil's attitude was always much lighter than mine. He was like, "Okay. Let's do it." With his usual lilt of voice and all. But it was real clear that we were both very concerned about the students, and that was important—because again as I said, we had their lives in our hands.

— 93 —

I kept also thinking I only agreed to do it for one year as a demonstration. I figured it was—for me it was a balance to be helping people with my computer skills, but it was my dream or my focus as a way to kind of give back. I remember going back and forth in my mind about that—that Sunday night. I think another thing—it was fortunate they asked disabled people to be doing the teaching. That—some of the students would come up with things—that we weren't disabled we could say—but because we were disabled we could say, "I can do it. Why can't you?" Whereas they could pull the wool over someone else's eyes. So as a result they had to get more creative, and I remember one time, one of the students didn't have their homework done and he explained that his octopus had gone into pneumonia shock that night.

Breslin: His octopus?

Luebking: Yes. He had a saltwater tank, and I thought—

Breslin: That's the epitome of the dog ate the homework—

Luebking: Yes. You've got to give him something for originality. So that was interesting.

Neil was really into keeping track of books, and I think that was helpful, because we knew where we stood in terms of the budget, and the rest of CIL did not always work on this basis.

Breslin: Yes. Neil probably kept track of things separately from the CIL structure.

Luebking: Oh, yes. Absolutely. So we knew exactly where we were at.

CTP administration

Breslin: Let me ask you just a little bit about the administrative arrangement. What were your respective job titles if you had them, and what were your supposed responsibilities? Were they divided up in any linear way? Or—

Luebking: Well, I was officially the director, or founding director, whatever, and Neil was my assistant.

Breslin: You were the founding director.

Luebking: Well. Yes, director, whatever. After the first year, we became co-directors for the second round.

Breslin: Was there a division of labor in terms of teaching assignments, or administrative—

Luebking: I did more COBOL—I taught more in the morning. Particularly when we were only going to do COBOL, and Neil wanted to do Assembler—so he taught Assembler in the afternoon. He also did some stuff in hardware, and so we had a lot of flexibility about

what we wanted to do. He also got a lot of advice from the business advisory committee.

Breslin: Did that advice prove to be useful?

Luebking: In a lot of ways, yes. I think they felt the project was their project, and so they took it on that way. We did some stuff like, one time—the part we were having problems with was that Neil and I, being so young had never really worked in business, didn't have that real life experience. So we made arrangements with one of the members of the business advisory committee members, so I could go and be in their office for three days, and just go to see what it was like and all that.

So I got there and they said I have to wear a tie. It was like, one of the worst three days I ever had; I would never want to work in this situation. I felt so guilty that I was training these people to go in that situation. I didn't know what to do, and I kept rationalizing it that this is their choice, and this is the reality of what they need to do in order to have money, in order to be able to—

Breslin: Not be poor—to not live in poverty—right.

Luebking: Yes. I kept focusing on that—this may not be my life, but it's going to be improving their life, so they would have to learn.

Breslin: Well, what about this was so difficult for you?

Luebking: Conservative people, the way they dressed, the problems, the computer problems that they were dealing with, it was like—someone showed me a problem that they worked on for three days, and I looked at it half an hour—I got the solution. It was just things like that. It was just very, very frustrating. I felt cramped.

Breslin: A radical difference between the way the business environment used technology, and your environment as a graduate student in a highly charged and challenging environment—

Luebking: Yes.

Breslin: Sounds like that was the basis for the conflict.

Luebking: It was again, a very different way of approaching computing. I knew it was going to be different, but again as you say, I came from Berkeley—one of the top computing science departments—so one of the things I sometimes realize that back where I come from, I take things for granted. I think that's where I came into the same problem.

Breslin: It had to have been useful though, for you to understand that maybe not all business environments were like that particular one.

Luebking: They were quite similar.

Breslin: I'm attempting the benefit of the doubt here—[laughs]

Luebking: [laughs] Neil went too—I came back so depressed that Neil felt that he had to go into one to make up for it.

Breslin: Was he as equally as unfamiliar with them as you were?

Luebking: Yes. But Neil can deal with groups of people in ways that I can't—so he's much smoother about that, and so he was actually quite happy with what he did. So we kind of decided that I wouldn't say much and he would talk about that. [laughs]

Breslin: You don't want to undermine your students' optimism about their futures. [laughs]

Luebking: Yes. I think one of the things that we had problems with—we had to deal with a lot of personal things. I was really kind of glad I had some background in counseling for that. I remember one Monday morning, by ten after nine we'd found out that one of the students had attempted suicide—nearly attempted suicide over the weekend. Another one had had a gun pulled on him by his roommate and something else had happened to a third one—and this was like ten minutes after nine—and Neil and I were basically working nine to eight easily. We looked at homework and all the stuff that we had to deal with.

Breslin: You guys were teachers and that's what you do as teachers.

Luebking: It was not—it was more than just teaching. We believed that we had to do this. Whatever the student needed to get through the program to get a job was what we were going to do. It meant training them to do attendants, and it meant helping them deal with paperwork, with DR, and with homework. If they were having personal relationship problems with their family—it was like just—you're a student, we're here to help you with your life at this point. So they could come up with anything with us. And we would deal with it. A lot of stuff we just winged it. We had no idea what we were doing, but we lucked out that through a combination of intuition and just creativity—

Breslin: And commitment—

Luebking: Yes. I think I just kind of take that for granted. It was like well, yes, we're dealing with people's lives, so, of course, you put yourself in that position. That doesn't make sense?

Breslin: Well, this is your interview, not mine. But, I think that if you would compare what you were trying to do with computer classes, computer technology classes at Cal—

Luebking: Well, this was different because we were—a lot of these people had never been out, I mean, they had been stuck in their home after being injured. Or they grew up in a very protective environment so we had to—the computers were being used as a vehicle to move them on through their life.

Breslin: That was my point.

Luebking: We had to be there for everything.

— 96 —

CTP: programming for independent living

Breslin: This is not simply a vocational training program. This is a total life, independent living training program that involved—

Luebking: Yes. Well, the goal was to have them doing jobs. So that meant, what do they need to do to be doing jobs? So it was a whole set of things.

Breslin: Did you imagine that you knew what those things were when you started? Did you have an idea that there would be so many kind of non-academic issues to deal with?

Luebking: Well, when I was in college, one of the things I did was—I did volunteer work as a crisis counselor for families. So I dealt with issues around incest and suicide, and I saw a lot of things. So I was, in a way, prepared for some of that. What I don't think I was quite prepared for was—when I was doing volunteer work, it was only two days a week or something like that—in this case it was seven days a week for many, many hours, and not only did you have problems with all the different people, but then you had all the problems interacting with other problems. It was very complicated.

Neil really needed to belong in a way that I didn't, and so I think I came off as a little bit more aloof, and I'm not sure if that was good or bad. But I remember when we had a set of boxes for all the students, and Neil had his box for the students, and this was just his way of it being part—but I remember after the second class, we were at a place where the students were and they were drinking. I remember one of the students who was kind of having a little bit too much to drink came up to me and said, "I could never tell you this if I were sober—but people thought that you were aloof, but I think that you actually cared more about me, but you just didn't show it in the same way." I remember that was very surprising, because I'm not always known for showing my emotions on my sleeve.

Neil was definitely the favorite of the students, which was fine. It was almost kind of like a mother/father; mom/pop type of thing. But in some very curious dynamics also. Because he could be more of a disciplinarian than I could in ways, but there's things that I could see in them that he couldn't. I had to kind of point things out to him. Not that he wasn't bright or anything, but we worked at different levels. So again, it was that combination—that we were able to cover for each other.

Neil was very hard working. I think that was very important to the project. He was more willing to be told what to do than I am—I tended to be more like, let me figure this out. And so I think that was—that was particularly helpful. I know that one of the problems we had with the students was dealing with credibility. It's like this was the first time that this program had ever happened—and the students would come to us sometimes and say—especially when they didn't want to do their homework—"Why should we be doing this, because we don't even know whether we're going to get jobs? This has never happened before." We had that happen several times.

I think we were just sitting around the office saying—this was again like, "What in the world are we going to do? We've got to figure out a way of motivating them." We can't—they're only half-way through the class or something like that—there's all this

stuff they've got to learn, and then we thought, "Okay. We'll come up with the idea of review boards." And this is how review boards got born. So we brought in the business advisory group and they would review the students.

Breslin: In class?

Luebking: No. This was after—they had to prepare stuff. I think we only had one review board though, the first year. But it really motivated them too, because they had something to work for. Someone to prove themselves to. In a way to be validated by someone from the outside world—that they really did know the material. We also thought this was a way for them to get to know each other.

Breslin: That was a networking opportunity for the students as well as—

Luebking: Yes. Yes. I think we also were doing—we started to do the internships that year. I think we only did like three-day internships as part of the exposure, and those eventually became six-week internships, and that's been—was another way of networking and there were people who got jobs through that.

Conflict with CIL

Breslin: Let me ask you a question about your relationship with CIL at this point. Because you guys were, you were still—CIL was still your fiduciary agent.

Luebking: Yes. We were reporting to Judy.

Breslin: Was that—how was that?

Luebking: Judy and I did not—Judy and Neil and I did not always see eye to eye on stuff. Neil and Judy had known each other from childhood. And some of the choices that CIL made again with finances were not decisions that we would go along with, so that created additional conflict.

Breslin: Are there particular areas of disagreement that are memorable between all of you, or—were they political in nature—or—

Luebking: Oh, I think there was some politics involved. I think there was—Neil and I believed that we had to show the computer training project for being fiscally responsible, and CIL's tradition was a little bit different in terms of handling money coming in and going out.

Breslin: Did you have any—either of you have any idea about its—the program's ultimate future at this stage? Like during this first year, did you have a sense that it might not remain under the CIL umbrella? Or were you even thinking that far ahead.

Luebking: Basically we would get up each morning and we'd have no idea what was going to happen to us. Literally, we had no idea who was going to do what to whom. We had students break in to get coats and set off the burglar alarms, we had—

Breslin: Where were you physically at this point. Where was the program at this point?

Luebking: On Milvia.

Breslin: On the second floor, is that right?

Luebking: Fourth floor. No—we had started at third and we moved up to the fourth floor after that. And I think it was—we probably didn't have any idea that this was going to be—go off and become so well known and be emulated in so many ways. I know that Neil was upset when I decided not to continue. Even though I'd told him originally I would only do it for one year. I decided to do it a second year, but I wasn't learning that much more.

I learned a lot of stuff the first year, and one of the things I did eventually figure out was that I really was not that good of a teacher at that level. I was better at a college or grad school level, because that's the way I would approach things. And for a lot of the students, you need to know something has a purpose in a computing process, and I think I was more of an academician type that—"Oh, this is really interesting in itself. Oh, plus it has application." So it was a different way, and I think I wasn't that good in motivating in that way.

We were really pushing hard to get people jobs and wanting to make sure that the time that they put into the program—they worked very, very hard—would not be seen as worthless. And we had a very high placement rate. We really pushed. We wanted to establish a good reputation, and so we did some arm twisting in the business advisory group. We did anything we had to to get jobs basically.

Breslin: How was the stay-put rate, you know, the retention rate in terms of jobs held over some period of time?

Luebking: I wasn't involved with the program long enough to know that, because I really only did that for two years. And Neil—this was his baby—this was his identity—again going back to his being disabled, and he was angry. He had thought I was betraying the program because I left when I did.

Employment at UC Berkeley, involvement in starting CIL's Deaf Services

Breslin: You went at the end of the second year?

Luebking: Yes.

Breslin: What other reasons did you have for leaving, in addition to that you had really learned what you could learn and needed to move on for intellectual and some professional reasons.

Luebking: It wasn't quite intellectually challenging enough for me. I was very glad to be able to help people. I realized I needed to—the reason I left grad school was it was intellectually challenging but wasn't helping people, so I needed to kind of find

something in between, and also, that first year my health had been affected. I was just sick much more often than I'd ever been in my life and realized a lot of it had to do with stress. And I saw a doctor over the holidays, and he said I really had to be less stressful, so I was cutting back on that—which I think was—that bothered Neil a lot because he was really working hard also. I was working pretty hard. I knew with too much stress, I would get sick, so that there was that piece of it.

I think probably, professionally, in terms of computers, I was really not going to grow in that area, so that's when I took some time off and then took a position on campus in the Travel-Demand Forecasting Project out of a research project on campus, and they were looking for someone who had a combination of math background, programming background, and it was just the last six months of the grant. So I thought, "Okay, if it's half-time, I'll try this, see what happens." It was a good match. I ended up running into somebody who knew that the person in charge of developing graphic software for the university, maintaining it and all, was leaving. So I went and applied for his position.

Breslin: And stayed with the university for a number of years after that.

Luebking: For five years. It was again one of those flukes that was the reason I had the background in computer graphics, because my freshman year I did an advanced seminar in—it was one of those independent study seminars in writing computer composed music, and I got tired of trying to translate the numbers into music, so I programmed the computer at that point, which is something you can buy off the shelf now. It didn't exist, so I just lucked out—right time, right place.

Breslin: Before you actually move away from CTP permanently—

Luebking: Well, I—okay—

Breslin: Go ahead—

Luebking: I was going to say the other thing I was doing at that point was—I was starting to learn sign language, and so I wanted to—in the first year, we didn't have any deaf people. So I wanted to have deaf people in the second year. So we were able to work with—we found a deaf quadriplegic and brought him in—so we had the interpreters, and we brought in another deaf person, and so that's how the tradition of deaf in the CTP—kind of from my interest in sign language poetry.

Breslin: It sprang from learning sign and being involved in bringing deaf students into the program?

Luebking: No. Well, I was very interested in sign language poetry, and so it just kind of—that's how I ended up meeting deaf friends and so forth and so on.

Breslin: I see. You actually had some relationship with CIL deaf services for—

Luebking: I was one of the people that started it—because I wanted to again do something different that I would learn from after CTP. The deaf quad had decided not to become a programmer, but was interested in doing deaf services. I knew that they were trying to do something with deaf services at CIL. So that's how I eventually got involved—

because I was only going to be working on campus part-time, and I thought that this was something I could learn new things with. I realized as my sign language got better over the years, my understanding of language and space was becoming more sensitive and more aware.

Then I started realizing that that's actually going to tie into my eventual work in computer human interaction, especially with graphical user interfaces, because you're presenting visual information, language, you're changing the relationships, so it's not just text and all, but it has to do with a lot more subtlety. And, like in sign language [pronounalizing?] space is where you establish pieces of space as pronouns, and you can do a similar type of thing as macros—visual macros and many, many different things. So my experience with deaf services—and getting to know deaf people and with the deaf advisory group really just supported a lot of it—again just lucked out with the combination of things that happened. So when I started to do user interfaces for artificial intelligence systems, it all kind of fell into place.

Discussion of CTP's existence

Breslin: Let me ask you something about the computer training program that has more to do with what was going on then in the computer world than what's going on now. I mean obviously anybody who's a programmer now pretty much has their—the world is open to them in terms of where they can work and the options that are available. At that point was there any discussion about creating a program that trained people with disabilities in one field—because they had disabilities? There was a tradition, for example, of training people who were blind to be piano tuners, or darkroom technicians and those kinds of things. People who had polio often went into speech therapy, because that was the "field" for people with polio. Was there any notion that the idea of a computer career—at a time it was beginning very much to build, but it certainly wasn't in the state that it is today—was that thought of in any way as limiting, or was it seen in just the opposite way?

Luebking: Well, I remember we had counselors wanting to jump to that conclusion, and so I tried to explain to them that it was more complex, but actually in a way I think we generally wanted to pull people into the program, so we were trying to open the horizons a little bit. I remember, I believe it was during the second year, a lawyer wanted to use me as an expert witness in a case where there had been a car accident and someone became a quad. He wanted me to testify that this quad's income was not going to be reduced because he could become a programmer.

Breslin: Oh, I see.

Luebking: And what my argument was that I remembered one of the professors once saying that if you don't like programming, it's one of the worst ways to make a living. So I called him and told him that and never got called back.

But one of the hardest parts, I think in doing the evaluation of students or potential students was how to tell some people no. I remember one time going to talk to one of the classes at Berkeley High School, a lifestyle class or something—I don't remember exactly what the class was. We just talked about stuff we were doing and all—and one of the students asked—what do you do if you're dumb and you're a quad—or if you're dumb and you become a quad.

And it was that type of thing where with some of these people, where they really wanted to see this as an opportunity, because it was like the only thing they could possibly do, it was very hard. Like they couldn't just go to another system—this was one of the few things that they had a chance at. And—yes—that bothered me a lot. Extremely. That's one of the reasons why I was glad when CTP started doing OST [office systems training]. So it was a wider range of people.

Breslin: And a lot of major job options when it was all done.

Luebking: Yes. But one of the problems with being a quad, one of the reasons why it was attractive was that the income from being a programmer could be high enough to replace what they would lose in terms of IHSS [In-Home Support Service], Social Security and all that.

Breslin: It was a rare opportunity for a lot of people I think, regardless of any of the political concerns. I think everybody looking back would say that, and would probably say that today as well. But it's interesting to think about the various reactions of the players of the time, putting together what is basically a segregated training program for people with disabilities, which has its—

Luebking: See, I don't quite see it as being—I heard some of the people commenting about that and kind of the way I was looking at it was they're going to be integrated after they have jobs. Let's give them the training wheels at this point and make sure they're able to do what they need to do.

Breslin: Was there anything comparable that people could have looked at commercially in the community?

Luebking: No. Not because of any—the strong integration of dealing with a person's whole life—it would be more a student/pupil relation, or something like that rather than—

Breslin: They could have taken a COBOL class, but they weren't going to get help with their attendant management or—

Luebking: Right. Yes. Seeing a person as a whole person dealing with a myriad of issues and maybe not having yet developed problem solving skills or communication skills or—

Breslin: In retrospect, do you see it as a model in ways that you weren't able to see when you were really very close to it?

Luebking: I know it's been replicated in places around the world, though from what I understand is that almost none of them have disabled instructors or leaders, so in some ways that was, that's different. We wanted to do something outside of the institution—some of them still belong to institutions, and again, that's different. I think we really—again the focus on transition. Helping people move from one state to another state.

Breslin: That was very unique from your perspective about this program as compared to other programs?

Luebking: Well, again, I haven't really followed it that much after I left.

Breslin: I mean from your perspective at the time.

Luebking: Well, but there was only one other program. We were like the second one. And again the first one was in an institution, so it was just a whole—

Breslin: Yes. Different.

Luebking: —different perspective. But it was more holistic, I guess.

Breslin: Yes. That's right. Just a couple more questions about it, because I'm sort of curious about the relationship the program had to DR as it got more firmly established. There were some detractors—

Luebking: Well, there's always—there's always contention.

Breslin: There was.

Luebking: Yes. There's always different types of contention. I mean there were some people who loved it and other people who didn't. Some people felt jealous that it was in one person's district and not their district. I mean—there are some real—or that it didn't have enough of the right disabled people in it—money cutting issues.

Breslin: It never had an easy way of it in terms of continuing on as—I mean it has been around now for some twenty some odd years, but it's—twenty-five I guess—

Luebking: In the beginning we were lucky after Ed became director of the rehab. It was like they gave a little bit of a grace period. But even then there were whispers.

Breslin: What was your legacy to the program?

Luebking: [long silence] I'm not sure I would say that there was—[silence]—it's a subtle one. I think, I'm not sure if I had not been involved, I'm not sure it would have succeeded because of the particular combinations of skills that I had. But I'm not sure if Neil had not been involved it would have succeeded either, so I think of it more like looking at a water molecule. That the water molecule doesn't exist if either oxygen or hydrogen is missing. And so I think I probably provided the hydrogen, and Neil was the oxygen.

Breslin: That's a wonderful place to stop.

Luebking: Okay.

III. Member of Cil Board of Directors, Experience At Trantech, and Work on Attendant Issues

CIL board and leadership concerns, 1981-1982

[Interview 3: July 18, 2001][Tape 3, Side A]

Breslin: Scott, we talked a little bit last time about your work at UC Berkeley after the Computer Training Program. During that period, you were also on the board of the Berkeley Center for Independent Living. What prompted you to join the board?

Luebking: I can't remember, somebody asked me. I really can't remember. I think partly it was to help bring some of the skills I learned outside of the community back into the community. Having been around CIL since literally the first few months that it started, I had a historical perspective. Back when CIL was still up in the apartments up on Haste Street.

Breslin: This was 1981-1982, so it had been nine years since CIL had just begun. What kinds of challenges did you experience as a board member?

Luebking: I think that it was fortunate that there were a couple of us there who had similar views, with Jessica Weld and Linda Toms Barker.

Breslin: She was on the board with you at the same time. Who else was on the board?

Luebking: I remember that "OJ" was on the board. "OJ" was the parking lot person, a real character.

Breslin: What was his full name, do you remember?

Luebking: No.

Breslin: What kinds of issues were you talking about, what kind of things was CIL working on or concerned with at that time?

Luebking: We were concerned about the directorship, that was an issue. Phil Draper was the director at that point. [tape interruption] There had been concerns about his abilities as executive director. Oh, Jack Rowan was also on the board of directors.

Breslin: What kinds of issues was the board concerned about in terms of his leadership?

Luebking: That he wasn't really up to the position of being executive director.

Breslin: What did the board do?

Luebking: We worked to restructure and had him move out of the position.

Breslin: How was that received within the organization?

Luebking: Not overly well. There were also people on who were concerned. Phil believed that CIL could not survive without him. That's the impression he was giving.

Breslin: Do you think the board was fully aware of everything that was going on within the organization at that time?

Luebking: No.

Breslin: Why do you say no?

Luebking: Because I knew stuff that was going on that I knew that other board members didn't know. It just happened because of connections.

CIL's community and political role

Breslin: What was CIL's role in the community during this period, '81-'82?

Luebking: CIL had a large staff. There was a lot of respect within the general community, and within the disabled community there was a fair amount of respect, still. Certain services were not as well managed as they could have been. There's also the way that money was being handled, and some contracts handled that definitely could have been improved upon.

Breslin: Was CIL playing a political role at this time in the disability community?

Luebking: Yes, both locally and nationally.

Breslin: What was its role nationally?

Luebking: I think it served as a model. It was an agency that could be pointed to, and then they were being used for providing advocacy and consulting for places that were starting up, and also giving input into policy issues in Washington.

Breslin: Are there any particularly memorable meetings that you attended which shed some light on the character of CIL during this period?

Luebking: There was a lot of contention within the staff. There were issues around the strike, and all that.

The strike period at CIL

Breslin: This is the strike period?

Luebking: Round then, yes.

Breslin: What was the strike about?

Luebking: Power and control, perceptions of how management should be working, respect for workers, things like that. Part of the problem was that there were people who were working for the first time in their lives. They hadn't really worked in the real world, so some of their expectations were not realistic. There were mistakes that management made because of inexperience and a lack of introspection. There were a lot of mistakes being made in many different directions.

Breslin: What was the goal of the strike and who called it?

Luebking: The strike was called by workers, I'd say. There's also some political beliefs that were coming in place, philosophical beliefs, there were a number of different aspects. There were a lot of legitimate complaints, but there were also higher expectations than were realistic.

Breslin: What kinds of expectations were those?

Luebking: The way an organization should be run, worker input into the process, policy decisions and things like that.

Breslin: Those were unrealistic, you think?

Luebking: Well, I think some of it was unrealistic and I think some of it was that if they had had better managers in place, there would have been less demand for resolution. So that there was no one side that was right.

Breslin: There wasn't an actual union that the members of the staff belonged to, was there?

Luebking: No, not that I remember.

Breslin: Do you recall whether any particular union was organizing within CIL for membership?

Luebking: There was some stuff, that since I wasn't on the board of directors, I wasn't aware of.

— 106 —

Breslin: What was the outcome of the strike?

Luebking: A lot of bitter feelings, to the point that they're still there.

Breslin: Was there any resolution to the actual concerns that workers had?

Luebking: I think there was some, but it goes back to the issue of control and power, and I don't think it was really fully satisfied. It also had to do with expectation management.

Breslin: Was a union formed at CIL as a result of the strike?

Luebking: I believe that there was something that was put in place. I'm fairly vague on some of this stuff.

Breslin: Were you on the board during the strike?

Luebking: Again, I can't remember if it was before or after what had gone on with that.

Breslin: Do you recall if there were any specific revisions or changes in policy that came about as a result of the strike?

Luebking: Nothing concrete that I can remember.

Breslin: Do you recall how the disability community itself responded to the strike?

Luebking: There was a lot of support for the workers.

Breslin: Did it overall strengthen or weaken CIL?

Luebking: Because of the damage to the relationships, I think that negatively affected it.

Resigning from CIL board, CIL management issues brought into focus, CIL's achievements and shortcomings

Breslin: Did you serve one year on the CIL board?

Luebking: Eighteen months or something.

Breslin: Why did you decide to step down or not run again?

Luebking: I resigned. I felt that I wasn't being particularly useful, that my perceptions seemed to be at odds with a lot of people.

Breslin: Was it difficult to move your agenda on the board?

— 107 —

Luebking: With certain key people it was fine, but there were a lot of other people who were coming from more of a theoretical point of view, rather than hands-on, having worked in the real world or something along those lines.

Breslin: Do you think the board was effective during this period?

Luebking: In some ways yes, in some ways not.

I think one of the most helpful things was to work with moving Phil to a different position.

Breslin: Was being on the board enjoyable for you?

Luebking: I think it was the first time that I really—. Even when I was at CTP there were problems between CTP and CIL. This took those problems and brought them into a clearer context.

Breslin: Can you just talk a little bit more about those problems that came into focus for you during that time?

Luebking: I think that the issues of how to handle money was a problem. People seemed to believe that they would be held to a lesser standard of fiscal accountability because of being disabled.

Breslin: Was that a passive message that was being sent, or was that overtly stated?

Luebking: It was both. There were a range of problems with being audited, and information not being found that was expected, and things being excluded from delaying, and stuff like that.

Breslin: What do you attribute those management problems to?

Luebking: Lack of experience.

Breslin: By everybody involved in the organization, or by leadership?

Luebking: By both—rather than looking at the big picture, they were seeing that they were getting money to do stuff with. It had to do with expectations. I know one of the problems that had to do with CTP was that [CIL] people wanted to shift money from different pockets in order to cut their bills and things like that. Then when they had to do reconciliation [with the grant money], there were problems.

Breslin: If you can step back from your board role there during the time, what was CIL's biggest achievement in the community during that period?

Luebking: I think that they brought a lot of very talented people in. They were able to be involved in things. A much greater recognition that disabled people were able to do stuff. I think that made a very lasting impact on the community. They also didn't understand the impact of their decisions during that period in terms of quality of service. That wasn't really being addressed.

— 108 —

Breslin: You consider that the least effective aspect of the program?

Luebking: As I may have mentioned, it was part of a pendulum where people were perceiving disabled people as not able to do anything. Then it went the other way and disabled people were right in whatever they did. To criticize that they were making mistakes was to criticize the disabled community, rather than looking at it as an opportunity to learn and expand skills and abilities. There were also problems because people would be hired because they were disabled rather than the qualifications they brought to the process.

Breslin: You think that people weren't qualified?

Luebking: There were certain positions that were hired for, where people made mistakes because they didn't have any experience or understanding. They were hired because they had a visible disability. They would be hired over people who didn't have an obvious disability because the idea was to have a role model versus—. Not understanding the impact—that having a role model that couldn't do the work reemphasized the stereotypes.

Breslin: Couldn't you then see a way that those two conflicting issues could be resolved?

Luebking: Not given the point that they were at in terms of understanding themselves as a group. And the very strong link that they have, in terms of disability. Still, there are sections in the disabled community that aren't very tolerant of criticism or anything like that.

Breslin: Anything else on the board?

Luebking: I don't think that is necessarily unique to the disabled community. There might be other minority groups with the same sensitivity.

Breslin: Do you think this is part of an evolutionary process of gaining your own voice or sense of identity?

Luebking: My reaction is that there is probably a good chance of that. It's also not clear how it ties into the younger disabled people not being involved in the disabled issues, and how it fits their identity. They may see themselves as people first rather than disabled people first, which in a way is progress, but it also focuses on integration. One of the consequences of integration is lack of commitment. It's a delicate balance.

Recollections of Judy Heumann and Ed Roberts

Breslin: Was Judy Heumann at CIL during the period that you were on the board?

Luebking: Yes.

Breslin: Can you share any recollections of her role during that time?

Luebking: Well, she was a defender of Phil. I don't quite know how she viewed the board of directors, but I got the sense it was not with strong respect. Phil would hide information from the board of directors, so I don't know her aspect in that. Then there was her position in the strike.

Breslin: What was her position?

Luebking: Being involved with the workers, and that sort of thing.

Breslin: She was sympathetic to the worker's issues?

Luebking: Yes.

Breslin: What do you think Judy's role overall was in respect to CIL, in political terms?

Luebking: The ability to reach out and make connections was highly valuable. She was great for bringing money in, doing awareness, that type of thing. In terms of being a manager, she was lacking with that. It would have been better if she had a role that was more clearly focused on external issues rather than the day-to-day running of the organization.

Breslin: Did you ever convey your thoughts about this to her?

Luebking: I'm sure I did.

Breslin: Was she receptive?

Luebking: She took on different points of view depending on the day and her vulnerability.

Breslin: Ed Roberts was still with the Department of Rehab at this time, is that right?

Luebking: Yes.

Breslin: Did you know Ed?

Luebking: Yes.

Breslin: What was your impression of his effectiveness in a leadership role.

Luebking: He was able to be seen as an external model that people could identify and relate to. He was effective in that way.

Breslin: Any other thoughts about Ed?

Luebking: I don't think he was a strong manager. I know there were issues about how he would view finances versus how the accounting board would view finances.

Breslin: Do you have any recollection of a particular impact of those years?

Luebking: [laughter] Yes, that's the year we got in a lot of trouble.

Breslin: Can you give us an example of that?

Luebking: Costs being denied, having to do refunds, stuff like that.

Breslin: Anything else that comes to mind about your CIL period?

Luebking: It made me more aware of how being on the periphery that I could enter and leave so freely. And I was also feeling very silly that when I first came to Berkeley, in terms of dealing with my disability, it was not a strong part of my identity but rather an aspect. I realized that I had the luxury of going in and out because I knew there were places I could go to. I was feeling that I was rather fortunate growing up and being exposed to a wide range of experiences and information that affect my perceptions. I see things in a larger context.

Employment at Transtech, 1983-1986, comparison with CIL

Breslin: Throughout this period you had been also working as programmer for Transtech?

Luebking: I was the user interface specialist for TransTech.

Breslin: What was that job about?

Luebking: That was actually after I left CIL.

Breslin: What was the time period for that job?

Luebking: '83 to '86, I think.

Breslin: Was that something you enjoyed doing?

Luebking: One of the reasons that I wanted to have a job off-campus was that after a certain period of time working on campus it's impossible to leave and go into private industry. They would look at it as a purely academic record. That's one of the reasons, after five years in academia, it was time to expand my resume. I had been approached a while back by some others, but I had always wanted to stay where I was.

I said, here are the conditions that have to be met for me to consider leaving. They met the conditions. It was interesting for me because I was the second employee hired outside of the [company's] founders. The first employee was hired the day before I was, and I could see how it was developing. I had to watch CIL develop, and see how this place was developing, and seeing the similarities and differences.

Breslin: What were the similarities and differences?

Luebking: I think that the difference was that it was a company being started by people who worked for much larger companies. They brought with them a wide range of experience. Some of the mistakes that were being made at CIL weren't being made there. I could see what those differences were. Some of the problems were that most of the founders had very little experience in terms of writing and managing lines of software code. That created some problems. Another issue was the role that people-user interfaces often fall into is the advocate for the user in the software development process. So with other engineers, they may not have that sensitivity and have to be more aggressive about that. I thought I was more aggressive with CIL in earlier times when I was dealing with stuff. There are certain things that I saw that enabled me to give more input into looking at this whole thing.

Breslin: That's an interesting comparison between a start-up for profit company and a nonprofit political advocacy organization. What were the kinds of things that looked alike and looked different?

Luebking: The measures of success. The strong focus in the start-up on money, wanting prestige, recognition, things like that. Short-term focus rather than long-term focus, so some of the mistakes that were made were on the basis of short-term gains versus long-term. Communication patterns, seeing how those evolved over time among the different people—. Conflicts in values, and how that was resolved. In CIL I saw more involvement around a philosophical and political point of view and ego. And at the start-up it was more the ego. Transtech went through a real financial set of problems.

Breslin: Why did you leave?

Luebking: I just finished my latest project with them, so I really didn't think I could learn anything more with them at that point.

Emergency attendant care services

[Tape 3, Side B]

Breslin: Let's get to an issue that is important to many people in the disability community, which is that many people need personal assistance services. In your experience, what are the issues people face in dealing with attendant services?

Luebking: Actually the broader perspective is needing attendants when there are none available for you at that moment. There can be two parts of that. One is needing an attendant because someone didn't show up, or needing an attendant because something went wrong and you need help at that point. Originally, problems cropped up because of some experiences with the later circumstances and then expanded into encompassing both types.

Breslin: There was a move in 1974 to begin talking about ways to provide emergency attendant services.

Luebking: I think it was '77, actually.

Breslin: 1977, and I believe that it was not until the mid eighties, 1986, when there was actually an organized effort to try to establish a program.

Luebking: There was actually an organized effort in '77.

Breslin: Talk about your experience with that.

Luebking: That was a very basic developing list of emergency attendants that CIL would keep on hand.

Breslin: What was your role with respect to that?

Luebking: Just brainstorming with people, I was just starting to work at the university, so I wasn't that heavily involved with it. We had our first initial meeting behind Top Dog at PDSP [Physically Disabled Students' Program] in the parking lot. [laughter]

Breslin: What evolved from there in terms of moving into an organized program? What was your role?

Luebking: At that point I was really focusing more on my professional stuff, so I didn't serve that much more of a role. I had just started working more at the university. Then, it was someone who went to the city in '86 and was asking to have money allocated from the [Berkeley] city budget. I was asked to be on the advisory board for the first organization providing emergency services.

Breslin: Did you say that you were the person who went to the city to seek money?

Luebking: No, I think that Peter Trier, Michael Pachovas, and Bronson West. They were the first, there may have been other people. I don't know the details.

Breslin: You were working with Susan St. Amour at this time. What was your role with her? What was her role with respect to—

Luebking: I was on her advisory board.

Breslin: She's the one who held the first contract?

Luebking: No, actually it was Bill—

Breslin: Frickman. Do you recall how all that took place?

Luebking: I don't remember the details.

Breslin: Was that a successful effort?

Luebking: He got the contract.

Breslin: Was the community satisfied with the service he was providing?

Luebking: It got to be a very political thing, partly because another organization wanted to have the contract and so they negotiated and did a lot of maneuvering to get the contract away from the first organization.

Breslin: What was your role on the advisory board?

Luebking: How to structure the attendants, talking about disabled people's needs, policy issues, dry things like that.

Breslin: Let me see if I've got the sequence of events correctly. Bill Frickman had the first contract from the city. Then Susan St. Moore got the contract later?

Luebking: No, it went to [Van-tastic].

Breslin: Another organization?

Luebking: That's right.

Breslin: Was the program successful? Was it able to serve the need it was set up to meet?

Luebking: You mean with that one, or—

Breslin: During the time you were on the board.

Luebking: I think there were things that were dealt with well. There probably should have been more education in the disabled community and things like that.

Breslin: A number of people have remarked over the years about how progressive Berkeley is with regard to these kind of services. This service, whether it's delivered well or badly, isn't available anywhere else.

Luebking: In this country.

Breslin: Right, in the U.S. So it's seen as a success in the sense that it exists. Were you thinking about it as a model when you were serving on the board?

Luebking: No, we were so much more concerned about doing it right so that the revenue stream would continue.

Breslin: So your focus was really management and effective operations?

Luebking: Probably underlying it was some thought that if this thing worked well then other places would make the connection, that it would be more of an offshoot until it could be well-managed.

Funding for Easy Does It, passing Measure E

Breslin: What's been its fate over the years?

Luebking: It was run by another organization for a while and there was another political upheaval within the community and it got transferred to another organization which is the current organization.

Breslin: What is that organization?

Luebking: Easy Does It.

Breslin: This is skipping ahead a little bit, but it might make some sense to talk about the bond measure a little bit. I know you've had a hand in it, can you talk a little bit about that?

Luebking: Funding for Easy Does It for emergency attendant services was coming out of the general budget for the city. The thought was that rather than having it compete each year with other organizations for money, there should be a separate tax set-up for it. That idea was being explored. When I heard about it, I was one of the first people to join the informal group to get it passed.

Breslin: Whose idea was it, do you think?

Luebking: I can't remember the person's name. It was originally proposed, then I think Donna Spring picked it up.

Breslin: This was a city council person?

Luebking: Yes.

Breslin: I was wondering if you remembered who from the community originally sponsored it?

Luebking: It was someone on the board of directors of Easy Does It.

Breslin: This person presented the details to Donna Spring?

Luebking: I'm not quite sure of the details of all that happened, but I think originally people spoke to Donna and it was picked up there.

Breslin: What happened then?

Luebking: I believe we started working to get it passed by the city council as a referendum.

Breslin: What was your role during that period?

Luebking: To work on a committee to get it passed, and making contacts and that type of thing.

Breslin: Was the council open to the idea?

Luebking: I believe it was passed 9-0, so it was pretty positive. The committee got very active into getting it passed, and raising money, talking to a lot of groups, sometimes two groups a night. The neighborhood associations, the different caucuses—there weren't many people active in the disabled community, it was a small, core group.

Breslin: Who was the core group?

Luebking: Michael Pachovas, me, and Mia Rudolpho, her brother, Peter Trier was involved, Phil Chavez, Karen Craig, these were basically the core people. I think Jean Nandi was involved in this.

Breslin: So what finally happened?

Luebking: There were a number of stages. One was getting the referendum written, and what was it we wanted and then they gave me an argument for it. We worked a lot with the city manager to get that written, and that was actually what was voted on by the city council. We were concerned about any arguments being presented in the voter's handbook. I believe it was the first initiative ever in the city that didn't have any opposition arguments. There were people that were concerned, but they weren't strong enough that they wanted to be seen as opposing disabled people. What eventually happened, the slogan was "Everyone agrees, vote yes on measure E!" There was very little formal organized opposition. Except for the Chamber of Commerce, there was some question about where they would go. That took a lot of lobbying.

Luebking: What was their opposition?

Breslin: They wanted to take a stance against any new taxes. There's a group within the Chamber of Commerce that wanted to take that approach. It wasn't so much directly against the tax as against all taxes.

Breslin: They weren't opposed to the issue?

Luebking: There was some concern about the issue, in terms of abuse. Some people in Chamber of Commerce just didn't want any new taxes. But I was working with the president of the Chamber of Commerce, meeting with him every day. He was very supportive of the whole thing. I ended up making a presentation to the Chamber of Commerce via telephone because their regular meeting was not that accessible.

Breslin: That makes a point. What's your view of the process now? Are you pleased with the outcome? Is the program working? Is it accomplishing what you hoped it would accomplish?

Luebking: I think there are a number of things still being worked on in terms of purpose and philosophy. There is a core group of people in the disabled community that wants to believe that anything they want should be provided by emergency services, rather than looking at the financial constraints and what we presented to the voters about the purpose of it. I think it's important to stay with the reasoning of how it was presented. Partly because that was what was voted on, and also what a lot of people don't realize is that this has to be renewed every four years. We need to maintain credibility on this. The renewal only requires fifty percent, and not the two thirds initially required. I think

that that's still an issue for some people. There are also some issues about the most appropriate way to be using these resources, and how to educate people. Another aspect that is coming out is that there are some people who might not be able to manage their attendants, and might need emergency services more often. How do we work with people who are having ongoing problems, where it's not an emergency but a chronic situation? What additional resources may need to be addressed for them? One idea is that maybe there needs to be facilitator available to a certain section of the population, people who are not quite ready to be fully independent but shouldn't be in a group home or something like that. That gray area.

Breslin: Of course, one of the wonderful local models is East Bay Innovations, which is involved in the developmental disabled community and does exactly that. But they're funded to do that.

Luebking: Part of the problem is for people who have the philosophical or political belief within Berkeley that disabled people can totally control their lives, and given the intelligence of a lot of people in Berkeley, that's reasonable. But Berkeley should not be a role model necessarily for what other parts of the country require, because of the high education level of the disabled here.

Breslin: What is true, I think, also, is that the people who receive in-home support services at a state level, the average age is sixty-five.

Luebking: The model is very different. It's sixty-five, woman of color—

Breslin: So there's a range of people who need a range of services. Some of them are totally able to manage their own people, and some of them are not. Not recognizing that need is extremely short-sighted, it seems to me.

An entitlement issue

Breslin: Anything else on the emergency services issue that you'd like to say, or that comes to mind?

Luebking: I think there have been some interesting experiences that have been showing up because of emergency services. One of the problems that has been seen on the national front is that California often sees itself as an entitlement whereas other people in other parts of the country don't come from an entitlement point of view as much. So there's been some discussion about whether this is an entitlement issue from a California perspective, and what does that mean.

Breslin: What do you mean when you say entitlement?

Luebking: Is a disabled person entitled to have all their needs met, or do they need to work in a cooperative way to get their needs met with having resources being made available? The issue of work—what I've heard from other disabled advocates in other parts of the country, is that disabled people in California are seen as wanting to be entitled for money, but not wanting to work for money. It's one of the issues that has come back from outside the community, is this an entitlement issue or not? One of my concerns is that there are people who are relying on the emergency services as an entitlement, but not necessarily wanting to be as responsible in taking control of their life.

Breslin: So when you say entitlement, you don't mean the literal meaning that it is a government subsidized program.

Luebking: But it is.

Breslin: But you don't object to that. It doesn't sound like that's at the heart of the issue. At the heart of the issue is the individual responsibility for the use of that program.

Luebking: Yes, the original model for it to be for emergency services, when a person has troubles or things go wrong in people's lives—

Breslin: People were using it inappropriately.

Luebking: Depending on your view of that.

Addressing the shortage of attendants

Breslin: Which actually gets me to the next question, which has something to do with your current work in the disability community around dealing with the shortage of attendants. What are your issues and concerns and what have you been doing about the issue?

Luebking: I'm working with a group, we've been calling ourselves the Personal Assistance Crisis Team, or PACT. We're looking at ways to address the shortage of attendants. The main focus has been looking at how to recruit students to do attendant work and try to reconstruct that working arrangement that we had in the seventies and early eighties with a lot of new students doing attendant work.

Breslin: Was this your idea?

Luebking: The crisis—

Breslin: The crisis wasn't your idea! [laughter] But the response to the crisis was.

Luebking: One of the things that I've been really pushing after CIL to do something about it. Then with the change in executive directorship, there was more recognition of the problem.

Breslin: Are you optimistic about the outcome of your effort?

Luebking: We're seeing it showing up now, in ways that—. Basically what I'm doing is looking at concepts of organizational change, and applying it to this situation. Organizational development and organizational behavior is a branch of business, and looking at how to change the relationship between the disabled population and the university students. The model I'm using is a psychotherapy model in a way. When a person is in psychotherapy, there usually isn't a major, sudden change. It's like working with a wire mesh sculpture. If you change the wire mesh sculpture, you're changing each of the metal wires one at a time. It doesn't look like a significant change until you stand back and look at what the impact is. The same in psychotherapy, and the same thing in relationships between the disabled population and the students, that we're making small changes in key roles. This summer we're beginning to see the results of some of the work. More students are looking for attendant work. This past semester, we were using the internet to do outreach and we've streamlined the communication between people who are looking for attendant work and people who are looking for attendants. Also using that ability to connect to key websites on campus, and also looking at tying it into a good system of [inaudible] on attendant work that we've been passing out at meetings. There's been a lot of personal contact, and each of the methods is representing a wire that we're changing in some way. Am I making sense?

Breslin: Absolutely. I'm wondering if you're able to measure success, are there numerically more people coming to the website to register?

Luebking: That's one of the ways we're doing it. One of the things we're using as a basis of comparison is that everyone who comes to the website is being contacted by CIL. We're seeing how many of them are responding to CIL's request to come in and fill in the form. Very few are doing that. We realize that we're reaching a population that normally would not want to come in through that process. That's making it easier that way.

Breslin: So they're actually applying on the web?

Luebking: They fill in a form saying the type of work they're interested in, what their background is, and so forth. That's being sent to a list of people who are looking for attendants. Also, the information is being captured by CIL.

Breslin: So it's an additional referral service, a recruitment and referral service.

Luebking: It's an expansion. We're bypassing the middleman, basically.

Breslin: Well, it's a great model. The internet aspect is excellent.

Luebking: At the WID [World Institute on Disability] meeting that they had on a qualified work force, we were seeing that there wasn't a lot of work being done on the internet stuff. We're kind of on the forefront about this. That is just part of the overall context. We're focusing on a population that is computer literate and savvy. What we think is being developed could probably be used in other university towns, but we don't believe it would really be useful for non-university towns. It could be expanded, but it shouldn't be the main thrust. We're looking for a population that are looking for part-time work, they don't want to do a lot of travelling, a lot of them are close to the campus, and this can be useful to them for applications for medical school. We're seeing that this can improve your experience and this can be helpful for the same reasons that people do volunteer work. So you get the advantages of doing volunteer work, but you also get money.

Breslin: Anything else on that?

Luebking: One thing that we're trying to address is the issue of fear and concern that people have about doing attendant work. We first try to make them aware of the possibility, but also structure it in a way where they can experiment in doing attendant work in very simple things like housecleaning. As they get more comfortable, they can do the more complicated aspects of attendant work. So we're using some of the concepts of organizational development by slowly pulling them into the process. Another thing that we're doing is stories, and looking at ways to use stories to shape values within the organization. One of the things we've done is make arrangements to have one of the campus fraternities doing attendant work, being highlighted in an article in the Berkeley *Daily Planet*. We started saying that you can be a frat member and you can do attendant work, that they're not mutually—.

Breslin: Be cool, be cool.

Luebking: Yes, we're kind of taking some of those aspects of reshaping the communication.

Breslin: You're doing all of this on a volunteer basis?

Luebking: Yes.

Breslin: Why are you doing it?

Luebking: Partly because of the way I was raised, that part of your life is for yourself and part of your life is for other people. If I weren't disabled, I would still probably be contributing in some way. In this case, because of having become disabled, I'm using the skills I have in that way.

Breslin: Has the community been supportive and collaborative on this process?

Luebking: I wouldn't say extremely collaborative. Part of the problem is that a lot of disabled people are burnt out on dealing with disability issues. There was a feeling when everyone was much younger was that they only needed to push for so long, and everything would come together—rather than a more accurate idea that it's going to be an ongoing set of issues. It's like maintaining the dikes in the Netherlands, you had to maintain them and when you didn't, things would crash. Fortunately, there's a lot of people that don't want to see that. It's a nice reassuring thing that I'll push for so long, and then it's over with.

Breslin: Anyone who is a student of history knows that it is never over with.

Luebking: But for a young population whose sense of history is only a few years, they don't have that.

Breslin: Let's back up a little bit to the mid-1980's.

IV. Private Sector Employment, Further Involvement In the Disability Community, Reflections on the Disability Movement, Details on Spinal Cord Injury

Employment at Sybase, 1988-1991

[Interview 4: November 26, 2002] [Minidisc 4]

Breslin: This is Mary Lou Breslin interviewing Scott Luebking. It's November 26, 2002.

Scott, we ended the last time with the idea that we would continue this time talking about your experiences in the Berkeley community around and after 1985 or 1986. I know that you worked at UC [Berkeley] during that time and that you took a little bit of time off, too. Can you just say a little bit about what happened in the last half of the 1980s?

Luebking: I worked in the computer science department on a grant, user interfaces for advanced databases, UNIX and using X Windows, in designs that were fundamental—the core stuff for that. And then I worked in a database company, looking at portability issues of software and designing tools to improve software design and implementation.

Breslin: What was the name of that company?

Luebking: Sybase.

Breslin: Oh, that's right. When did you start working there?

Luebking: 1989, maybe '88, something like that.

Breslin: What prompted you to decide to go back to the private sector?

Luebking: The grant was up. It looked like they weren't going to be renewing it. I had a friend who was working at Sybase, and it was in Berkeley at that point.

Breslin: So it was nearby. That was one of the incentives?

Luebking: Right, it was nearby.

Breslin: Was the Sybase experience a good one for you in terms of being a match with interests and skills and so on?

Luebking: In some ways yes and in some ways no. There was a lot of politics that went on there, and the politics got very challenging at points. And then one of my managers said I didn't know how to work with average-intelligence people, and that was a problem.

Breslin: Did you agree with that?

Luebking: I don't know how to quantify that whole aspect of it, but I think there was a gap between what I was able to see in the future and what they were able to see in the future. I think there was a little bit more of a focus that was more short term.

Breslin: Was the work you were doing there interesting to you intellectually?

Luebking: I actually got involved with several different things, where I was involved: competitive analysis. I was asked to evaluate products of the competitors, and I loved that. And I was asked to write the standards for the software for the corporation, or corporate wide, and learned a lot that way, and then designed and distributed a billing system for software and talked about portability issues: how to make software run on multiple platforms. And I was looking at abstract ways of understanding the software, and then looking at how to do X Windows in multiple platforms. X Windows serves as the graphical basis of Windows and UNIX environments.

Breslin: You left Sybase in 1992? Is that right?

Luebking: 1991.

Breslin: Was that an amicable parting?

Luebking: Mmm.

Breslin: Were there benefits to you in the end?

Luebking: Yes. I was more hopeful for being able to resolve stuff than actually occurred. I should have left sooner.

Breslin: I understand that you made some sort of arrangement with them that enabled you to have some financial independence as a result?

Luebking: Yes.

Breslin: That's been a good thing, in the end?

Luebking: Yes, I think so.

— 123 —

Need in disability community for technology communication, 1994

Breslin: Okay. In about 1994, you became very involved in various projects in the disability community. I want to talk a little bit about some of those, but I'm wondering if you could think about what was your impetus for deciding to become involved in the disability community again.

Luebking: I think that the main thing that happened was I started to see that the stuff I had been doing professionally for a very long time was beginning to—how should I say this? The disabled population's needs in terms of technology were beginning to reach the area that I had done a lot of work in, whereas before it was a much wider gap. And so it was—having lived in two different worlds at that point, because for the most part, because I'd been doing user interface, stuff since the early eighties, and most people only thought of me as a programmer, but what they didn't understand was that I had gone into computer graphics, and a lot of people in computer graphics had moved into user interface stuff, because it was graphical user interfaces.

It was a natural transition for a certain group of us. But the disabled population's access to computers hadn't reached that level yet, and since my disability doesn't really affect my interaction with computers in that way, I was able to keep up with the changes in the technology.

And then when blind people were getting more aware of what their needs were and some of the implications, that kind of made me think—understanding the problem from the background of having designed the user interfaces from a visual point of view, and you could kind of see where things had to be done.

But I'd say the main thing that was different for the first piece—well, actually what had happened was at one point Berkeley Systems asked to meet with me and talk about some of the problems they were looking at for their screenware "OutSPOKEN."

Breslin: And is Berkeley Systems a software developer?

Luebking: Right. They did software, like the game, "You Don't Know Jack" and screen savers and things like that, but part of them had also been doing screenware development. So I was asked to think about some of those things.

Breslin: Do you remember what year that was?

Luebking: Not exactly.

Breslin: Mid-1990s or early 1990s?

Luebking: I'd say probably a little bit earlier, like maybe—probably before 1995, '93. I'd been using Internet e-mail since, like, the seventies or so, but I started seeing that more of the general population was getting involved. [Sirens start in the background.] And since part of my interest has been about how information is shared and distributed through electronic communication, and looking at [sirens stop] some of the [inaudible] of online communities—how with themes [they] serve as the basis of online communities, a lot of

which is usually a need for shared, specialized information—and also having seen the disabled community that was physically pretty connected in the seventies start getting more distributed as people started moving out from the central part of Berkeley and all, that the need for the communication was still there. But the opportunities for the communication were accidental, and spontaneous communication wasn't there.

So, since spontaneous communication can lead to sharing of ideas, where people have a sense of something but it's not clear enough until they interact with someone else, it helped, through that process, refine it, and I was looking for ways of doing more spontaneous communication.

So taking some of those underlying theoretical concepts, I thought, well, the real simplest solution would be to set up a mailing list, and this is kind of how the Berkeley Disabled List evolved, because it was a virtual online community need. It could serve as spontaneous communication because people could read what other people posted and get them thinking about something.

Breslin: The Berkeley Disabled Mailing List is an Internet-based listserve—

Luebking: Yes.

Breslin: —that you established to accomplish this communication that you're talking about.

Luebking: Right.

Breslin: And what year was that? Do you remember when you began it?

Luebking: I can't remember whether it was '95 or '97.

Breslin: I'm looking at you because I'm thinking it's earlier, but—

Luebking: Maybe. The needs I saw in the population was, again, specialized knowledge being disability and location. Where there were other discussion groups that were based on disability, there wasn't anything based on location, and that I believed it was important to allow people to share information which was more Cal based, because of the ability to get better answers, better results for what they were trying to do.

Breslin: At the time you set that up, it was a more difficult technical challenge than it might be today.

Luebking: Not really.

Breslin: It wasn't?

Luebking: No, not really. We still used a regular, standard listserve program.

Breslin: I'm thinking that, for example, Yahoo makes—anybody can set up a serve now, without any technical background.

Luebking: Well, the difference was this made the capability for listserves to be usable by a wide range of people. In this case, my technical experience was enough where I could deal with more complicated things, so it didn't serve as a barrier.

Breslin: Right. My point was that it took your level of expertise to be able to set it up, whereas now it's relatively easy to set them up.

Luebking: Yes.

Breslin: But at the time, it did require someone with your kind of knowledge and capability to establish it.

Luebking: It was easier with that background.

Breslin: Did you have an expectation of how it would be used?

Luebking: There's something called OMUD, and it has to do with an object going to multiple-user domains, and it's kind of taken some ideas that are—

Breslin: Wait a minute. Is that the acronym? Object Oriented Multiple-user [sic; Multiuse] Domain?

Luebking: Something along those lines, yes. I'd been doing some stuff with OMUDs before that, and just getting people being able to communicate allows for ideas to develop because often you have a situation where they have a combination of the problem not being well defined and not understanding how the problem could be broken up into sub-problems, each of which other people may have the solutions. So the idea is by getting people being able to share communication, they can help refine and understand the problem, and there's an opportunity that—there's a possibility that there are people out there, each of whom have a piece of the solution but not the full solution, so by bringing them together, then you have a rare chance for problems being solved.

Another nice thing about it was you have an asynchronous nature of it, whereas OMUD is more simultaneous. Asynchronous means that people can participate at their own level of availability, so they don't all have to be available at the same time.

Breslin: No more need to be in the same room or on the phone or in a meeting situation.

Luebking: Right. Again, with the OMUD, in that case, you have to be online at the same time. So I actually toyed around with the idea of setting up an OMUD, but I thought that was going to be more complicated. That complication might be as a barrier. But the idea of e-mail, I thought people would be able to pick up pretty easily.

And the other thing I liked about it was it was what's called an example of push technology. They don't have to be proactive to get the information; the information is sent to them.

Breslin: And the mailing list has been operating now for five or six or seven years, at least.

Luebking: Yes.

— 126 —

Breslin: What's the outcome been in terms of your expectation?

Luebking: I think it served a number of purposes, one of which is someone saying, "I have this need for this type of information" and someone else saying, "I have some information. Check this out. Call this person," something like that. So you have shared local information going on. It served as a forum for being able to discuss local issues which were relevant to the disabled community, so you can get a sense of different perceptions, different needs, and by doing that, you have a better chance that the outcome is going to serve a wider range of people.

So information sharing, having a forum, and then also being able to send announcements out of upcoming events or new, changed laws or something like that. So I think in a lot of ways it's been serving that purpose I was hoping it would serve. It kind of reinforced some of the conclusions I had reached in online community stuff. So it kind of reaffirmed that.

I think the harder part was at the very beginning, getting people to understand that this was something helpful. The technology still was kind of new. They weren't quite sure how to work with it, again because of the level of technological sophistication. [Phone rings.]

[Tape interruption.]

Breslin: All right. So you were mentioning that it was difficult at the beginning to get people to feel comfortable using the technology.

Luebking: I think it was a little bit uncomfortable. Maybe the other reason was that they didn't have a clear understanding of the benefit versus the amount of effort they would have to put in to do it. And since they didn't have enough experience, they didn't understand the minimal amount of effort that was going to be needed for their part. So I ended up having to—like, I wanted a name that people could easily remember. I set my AOL screen name to be rescripted, because it's something that is easy to remember and also it has some internal alliteration which can serve also as a memory cue, figuring that if they could at least remember the e-mail address, that would be the beginning of a point of communication and they'd want even more.

Again, the experiences I had with how people think about information, interact with information, came in in constructing that. As more people got involved and started seeing the benefit of it, and they started telling other people.

Breslin: How many people are on the mailing list now, do you think?

Luebking: I think it's about three hundred and twenty-five. It's pretty stable. It went up and down for a while until you got to Yahoo, and then the transition to Yahoo made it more stable, and I think the main reason is we were able to get digest mode.

Breslin: So people weren't getting as much mail?

Luebking: Right. So for people who want to be kept abreast but not be inundated, that made a difference, because up until that point, it was pretty predictable: as soon as there was a

lot of traffic about one small subject or something like that, the number of subscriptions that would start coming in would go up.

The other approach I was taking for this was of it being the first line of communication. The idea was to have as many people involved as possible so that if something did get more specific, then what I wanted to do was allow them to be aware that each other existed, and then use that information to go off and start other groups, have off-line dialogues, something like that. The idea was to keep as many people on the mailing list as possible in order to serve that purpose.

Does that make sense?

Breslin: Oh, sure. You know, there's been much made of the Internet as a new way to organize within the disability community, and I'm wondering if you see the Berkeley Disabled List as one of the tools that has contributed to that perception.

Luebking: I think in general many groups that need to organize, for whatever reason, have found the Internet to be a very useful tool. Like, I just saw something on ABC News last night about people using the Internet to organize around Iraq, and they had people who had been involved with the antiwar movement against the war in Vietnam being able to talk about their experience in the sixties versus during these days, and just how much more efficient it is to get three hundred people to do something, because of the speed of the Internet and also the ability to pump out information.

So the ability to send information in a short period of time is a key factor, I think, in the organizational ability. I think that some parts of the disabled community have taken advantage of that, but I think there's also parts that have not, and that might be tied into some of the architectural, the technological barriers that some disabled people have to deal with.

Access Barriers to Technology

Breslin: Let's talk a little bit about those barriers, because that's been at the heart of some of the other technology work that you've been involved with in the last five or six or seven years. In particular, there are issues that you've been concerned about that have to do with people with vision impairments or who are blind, and access to computer technology or computer graphics and various kinds of programs at ATMs. Talk a little bit about what those issues are about and what your role has been.

Luebking: I think the first major one I dealt with was the access to web pages and browsers. That's when I started doing outreach to Netscape, to get them involved. Up until that point, the general disabled community in technology was unaware of me, since most of my endeavors had not been in disability. I know that when I first started sending information out to people, saying, "I've got an appointment set with Netscape to talk about the issues," there was a wide range of reactions to that, probably, again, because no one knew about my technological background. That was kind of a problem.

Second of all, because I was a sighted person rather than a blind person. And an additional complication was that I had gotten access to the senior vice president for engineering at Netscape and being able to set up meetings and all, where other disabled people had worked for a long time got no place. But I think one of the differences was because I had worked in software companies, I kind of knew how most likely the structure was inside, so I knew who to talk to and what words to say in order to get access. So there was that problem, that I was kind of seen as the new kid on the block and had accomplished some stuff that others hadn't. And there are still some people upset with me about that part of it.

When I designed graphical user interfaces, I usually design them from a very abstract point of view so there are less aspects of it, have to do with rendering or the presentation. But because I work at a little bit more abstract level, the information architecture, then the question became how do I shift the architecture to accommodate both visual and non-visual.

Again, this ties into this other work that I was doing with software portability and actually goes back to an even earlier time, when I was working at Berkeley and writing graphics software, where I had to write graphics software that would work on screens, on pen plotters and plume generators and a whole variety of things. The concepts I picked up there, in terms of abstraction mechanisms, and also the abstraction mechanisms I worked with in software for portability for different UNIX operating systems and things like that all kind of came into play.

Another aspect of it was that in order to understand how graphical user interfaces worked by saying the interface could not be graphical, that gave me a better understanding of graphical user interfaces.

Breslin: What kind of impact did you have with Netscape?

Luebking: I think we definitely raised their consciousness in terms of the legal department. We had fairly good interaction there. The engineering department made it pretty clear to me, was that it was not a revenue issue.

Breslin: It was a revenue issue.

Luebking: Was not.

Breslin: Was not a revenue issue.

Luebking: So the problem was how to make them understand that this is something to really consider. I think an additional problem was that it was well understood in some ways by the disabled community, what it is that they want in terms of the technology and that they have—in some ways, their lack of experience in the technological field was holding them back for understanding options.

I shouldn't generalize—of course, there were other disabled who really understood the technology quite well, but in general, I'd say their background was not quite strong.

— 129 —

Breslin: At the same time that you were working with Netscape, you also were beginning to get involved with other user interface issues, like ATMs and—I'm not sure what other projects, but can you just enumerate a little bit some of the other activities that you were involved in?

Luebking: I worked with doing some technical advising on the first ATM lawsuit and was looking at ways that ATMs could work best for visually impaired people, and also was giving advice in ways of structuring that discussion with the banks and helping to clarify what were reasonable options.

Breslin: What was your impact?

Luebking: Since there were a group of people involved, each bringing expertise from different areas, I'm not sure I can identify clearly what was the impact. I know I had some impact, because—a real simple one, with Wells Fargo: I suggested that they need to include, not only look at the issue of the blind person using the equipment, but they had to look at how the blind person would be learning to use the equipment.

Again, one of the things I was interested in is not only the technology, itself, but the infrastructure around the technology. In this case, it boiled down to if a blind person is using the ATM and needed some assistance, then a sighted person won't know what the blind person is hearing. So I suggested that banks also not only be given headphones but be given Y-jacks, so a Y-jack could be plugged into the ATM and then both the blind person and the sighted person would hear the same thing. And so if the blind person kind of got confused about what's going on, the sighted person could help with prompting.

Breslin: And did they adopt that suggestion?

Luebking: Yes.

Breslin: The lawsuit that you mentioned wasn't an ADA lawsuit?

Luebking: Yes.

Breslin: And just briefly, what were the issues involved?

Luebking: Well, basically because the bank is offering a service and is an accommodation that sighted people can use and that therefore it should be accessible to visually impaired people. Really shrink it down to a central issue.

Breslin: The ATM issue began, I think, with the litigation, but it's expanded now as a number of banks, nationally and internationally, have begun to adopt the technology. Is that right? Is that your understanding of what's happened?

Luebking: I think what happened was up until that point, the banks could say, "We can't do this because there's no place to point to." And that having to break that barrier—so this is where that lawsuit was very important, was that it got the bank to cooperate, but even more, once the ATMs was installed, it served to show that it could be accomplished and that technologically it was reasonable. So for banks who were up until that point saying that it's something that they can't do technologically, the argument no longer exists. So I would say that's a very key thing.

I think one of the problems that's still going on is they needed to look at the issue of how many blind people were actually using the technology, and that I think the technology needs to be reviewed in a way that it will be simpler in the future to develop dual interfaces, dual interfaces that can be both visual and auditory. And the more that they're integrated, to some degree, the less development time is going to be involved, which means that it's going to be not as costly for developing.

Breslin: It seems to me that your involvement and other people in the technology world involvement, coupled with the incentive of the ADA, has created a kind of a platform that everybody can now turn to, and taken together, the two have had a very terrific impact.

Luebking: I doubt it would have been accomplishable without the ADA.

Breslin: I think the two had to come together.

Luebking: I think first there had to be—if the technology had existed—the technology in itself is different enough for use for blind people, as compared to sighted people, that it requires more development effort and so that companies would be more resistant to doing it, so that's why I think the ADA had to be there, in order to encourage that. Again, the ADA, without the technological availability, would have gone no place.

Teaching at School of Optometry, UC Berkeley; helping to develop chemistry model for blind students

Breslin: You've also been involved in other activities that were linked to disability, including working with the School of Optometry at UC, Berkeley. Can you talk a little bit about that?

Luebking: Yes, that kind of evolved from going for an eye exam and having some problems getting an eye exam and then offering some suggestions and meeting with Dr. [Edward J.] Revelli, who was the assistant dean for clinical services there.

Breslin: What's his name?

Luebking: Revelli, Edward Revelli. And then, over time, developing ideas about how to work with that. At that point I was also doing some mentoring in the M.B.A. program at Berkeley, in a new product development course, primarily focusing in on technological products. But also I was interested in technological products in user satisfaction, in customer service. So some of the stuff that I learned through that could be applied to the optometry school, for patient satisfaction and specifically disabled patient satisfaction. So it was kind of pulling in a number of different backgrounds into that.

Breslin: You developed a curriculum and actually taught there in the last year.

Luebking: Yes, the past few years.

Breslin: Couple of years.

Luebking: I think I've been lecturing there about three or four years now.

Breslin: Are you pleased with the outcome of your collaboration?

Luebking: Oh, yes. I think this is the first year we've had—we replicated what we did last year, and we got, again, positive results, so I think we have it pretty well fine tuned right now. The feedback that we found from students from the online survey has been extremely positive. And I think we had—I don't remember the numbers offhand, but on a scale of one to ten, I think we ended up, like, with an 8.5 from the students. So we're pretty happy with that. Either 8.1 or 8.5, something like that.

Breslin: That's very great.

You've also been involved in a couple of other issues: health access and voting equipment. Can you talk a little bit about those two?

Luebking: There's also the chemistry project.

Breslin: Right. In whatever order you prefer.

Luebking: Well, the chemistry project was a project for a National Science Foundation grant to use web technology and speech recognition and plastic models to teach blind students about chemistry models. It was kind of using a wide range of off-the-shelf technology in some new ways. It was kind of using ways to navigate through auditory tapes or auditory recordings, but we were doing it by controlling it through web pages, and then what we were able to do was generalize that to have the web pages controlled by speech recognition. So we had speech recognition controlling web pages controlling sound output.

The advantage to that is that a blind person could keep both hands on the model, explore the model, and then, as they want more information, they could talk to the computer, and so that way their hands didn't have to leave the model.

Breslin: That's great. Is that actually an up-and-running process now that's available?

Luebking: Yes.

Breslin: How widespread is its availability?

Luebking: I think it was more a feasibility project, to show that it could be accomplished.

Breslin: Has anybody taken it up from a marketing perspective?

Luebking: I don't think so. I think the market would be very small for it. But I think the concepts—there was some question about whether this could be developed using, again, web technology/speech recognition in models, and just trying to see if it was possible.

Breslin: Is this a recent project?

Luebking: It was pretty much done last year, finished last year.

Breslin: Has a report been written on the project?

Luebking: Yes, I believe so.

One of the other things that was kind of interesting with the project was that it showed how a well-balanced team, working together, could accomplish some very positive results. What we were doing was we had a subject specialist who had his Ph.D. in chemistry, who happened to be blind, and then we had a technology access specialist who was aware about screen readers and knew that side of the whole thing, and then in my case, I wasn't bringing so much to the disabilities aspects into play as much as the computer-human interaction and, like, the programming aspects of how—we ended up having—I wrote a XML parser Java script and brought the notions of event table handling so we could map into a wide range of events for controlling the sound. Again, a lot of techniques I had from designing user interfaces, visual user interfaces I was able to bring to sound controlled interfaces, voice controlled interfaces.

Breslin: How'd you get involved in it?

Luebking: Your fault.

Breslin: [Laughs.] Really?

Luebking: Yes.

Breslin: I actually don't remember. Remind me.

Luebking: You told Dennis to call me.

Breslin: Oh. Dennis Fantin.

Luebking: Yes.

Breslin: Who was Dennis? Just for the record.

Luebking: Dennis was the guy who got the grant from the National Science Foundation. He's a blind chemist.

Breslin: At UC Berkeley.

Luebking: Yes.

Promoting technology for voting access in Alameda County

Breslin: Do you want to talk a little bit about either voting and or health care access issues?

Luebking: The voting access issues come out of my interest in human-computer interaction and also blind access issues. One of the things, in the eighties I worked on developing a touch-screen, artificial intelligence application, so I had a fair amount of experience with touch screens. So working with touch-screen applications for voting equipment, I had a pretty good understanding of the issues.

One of the things I had been kind of toying around with was an idea of blended interfaces for command-line interfaces and also basically interfaces that could be controlled either by command line or by mouse, so for sighted people, they could control it by mouse and for blind people, they could control it by entering commands into a command line. So I started looking at how some of those ideas could be applied to voting equipment.

Breslin: There's been a major upheaval in voting since the 2000 election, the presidential election, and much of that upheaval has drawn attention to the effectiveness of the paper ballot, and subsequently there's been a move toward developing alternative technologies.

Luebking: Yes.

Breslin: You've been very involved in the development of the accessibility, usability features of the touch-screen equipment. Can you just say a little bit about not so much the technology behind it, but the politics and impact of the work that you've done? At least locally.

Luebking: I think some of the impact has been basically at least working with the voting equipment developers for the equipment that's being used in Alameda County and being able to help educate them about some of the needs for the access for disabled people in the county. Part of that came from working on developing what's called usability labs and running tests over at Berkeley City Hall, where we had disabled people coming in and using equipment, and then we had people from the developers coming in and watching, and we were also videoing it. And then they could start getting an understanding of what some of the problems are.

Also, that shared experience helped improve the communication I had with the company, because we could talk about the same thing, whereas before then, their exposure to disabled people was more limited, and so when I was trying to explain something to them, they hadn't had enough experience watching, and so that kind of served as a little bit of a barrier. But the shared experience also started opening up a better understanding of what possibilities could be involved.

Breslin: Why did they agree to do at all?

Luebking: [Pause] Part of it was their interest in making it go smoothly in Alameda County, and so they want to—

Breslin: I'm sorry, when you say "they," you mean the manufacturer.

Luebking: Right.

Breslin: Who's the manufacturer?

Luebking: At that point it was called Global, and Global was bought by Diebold so now it's Diebold Election Systems.

Breslin: Why did they want it to go smoothly in Alameda County?

Luebking: Because they want to sell in other places. The more places where they got positive experience, the easier it's going to be to sell their systems. So there's that part of it.

I'd also spoken before to some of the supervisors about the importance of accessible voting equipment.

Breslin: The county Board of Supervisors.

Luebking: Right. My impression is that the company saw me as someone who understands the disability issues, but also I could go and talk to the technological issues, so I was bringing both sets of knowledge.

Breslin: Your contribution, I think, has gone beyond the technologic side and has moved into the political arena. What do you think the impact is of the work that you've done in Alameda County?

Luebking: [Pause] One of the things it's kind of done was it exposed me to election officials throughout California, and I was able to do a presentation to the California organization for election officials called "Don't Let This Happen to Your Mothers." It was a thing on introducing usability and accessibility to the election officials, so when they start looking at equipment. Because of that, then there's a greater understanding of the importance of having regulations which require accessibility. The first way to show that was achievable, and then by showing it was achievable, then we also could show there was a need, so it was combination of the two.

Sometimes explaining need is a little bit harder when it's in a vacuum, but when you have a need and you have a potential solution, it helps to better understand the need, I think. Does that make sense?

Breslin: Sure. There was an interim, midterm election this month, a national midterm election, and a number of people reported on their experiences voting in Alameda County using the new touch-screen equipment, people with disabilities reporting on their experiences, on the Berkeley Disabled Listserve. What was the overall impact, do you think, of your work on their experiences?

Luebking: I think one of the things that happened was that they become more aware that the equipment was going to be accessible, so I think that they were more willing to try, whereas before, people often did more absentee ballot voting. So I think that by their being aware that there's this new equipment out there, they were willing to venture out and try it.

I think something that was a little bit more interesting was actually going and watching the polling staff working with the equipment and working with disabled people and to confirm that part of the accessibility problem that exists is not the equipment, itself, but it's, again, the infrastructure around the equipment: how well the staff understood the equipment for accessibility. I did not hear of any complaint that was directly attributable to the equipment, itself. It seemed at first that in some cases it was the equipment, but through talking with the people what became clear was that it wasn't the equipment, but it was the way the staff thought the equipment was supposed to be used, was the problem.

So it really just emphasized to me that accessibility of the equipment has to be the equipment, itself, plus making sure that there's this support system around the equipment for the accessibility needs. I think that's going to be a harder sell. Hopefully—I'm kind of preparing a small report on this experience, to start getting people more educated about the need for the proper infrastructure around the equipment and hopefully maybe getting into some sort of law or standards or something.

I think the other thing it helped is—there will be a limit to what the equipment is able to do in terms of not all disabled people will be able to vote independently. The more complicated—especially with multiple disabilities, it's just going to be hard to achieve that.

One of the problems with the evaluation of achievability is that people need to think about not only can the disabled person use the equipment but can the polling people set the equipment up? It needs to be designed for both user groups.

One is the off-user group in terms of being the poll worker, but when I design user interfaces, I don't think of it in terms of a single user group, but I think of a user interface as being a family of users, so you have different types of users. For example, you have a user interface that is for the target user but also you have the user interface that provides for the needs of the technical support people, and that the user has to rely on the technical support people in some situations, but if the interface was not designed to support the needs of technical support, then that's going to lead to decreased satisfaction for the user.

Like, when I design user interfaces, I have this idea, this concept of basically with the technical support, kind of ask the user interface, "How are you feeling? What's going on?" And—

Breslin: A means of getting feedback.

Luebking: Right, to get status and things like that. And so I think this needs to be also taken into consideration for designing the voting equipment, that it really needs to be at least two different populations, designed for.

Breslin: After the election, there were a number of people posted on the listserve, on the Berkeley Disability Listserve, and though certainly some people had problems, many people posted glowing reports about their experiences with the touch-screen equipment and how accessible and usable it was. I'm wondering if you can connect the dots in

terms of your contribution to that process. I understand it's evolutionary and always needs to be improving, responding to new needs and new technologies, but if you look at that one slice of experience that was reported, a lot of people felt that it was a terrific experience.

Luebking: I'm not sure how much I can say I contributed to that. I think that the equipment that the county had chosen was the right equipment, as a baseline. While not perfect, I could see that it would go in the right direction.

Breslin: All right, but what was your contribution to the selection of that equipment?

Luebking: Actually, that had occurred before I got involved with the process, because they had already made the choice of the equipment. The part that I became involved with was convincing, helping to convince the supervisors to put the money out for buying the equipment. Because at that point, they thought they would go for it, but they weren't sure, and so that's why I ended up having to argue that for a nondisabled person, this jump to technology would be helpful, make things a little bit easier. It doesn't compare to the amount of freedom and independence and satisfaction that would have come for disabled voters. And so I'd say I was probably helpful in some ways along those lines.

I think the other area that I was probably—

"Online Shout" facilitates health care access

[Minidisc 5]

Breslin: Scott, I'm sorry to interrupt you. Go ahead with your thoughts about the ability of e-mails to last forever as a means of providing feedback to Alta Bates [Hospital] about your services.

Luebking: It serves a couple of different purposes. It shows that people are concerned about it and that with voice mail being ephemeral, people can forget, but if it's in e-mail, you can resend it again and again and again to remind them.

Breslin: So what was the response of Alta Bates to getting feedback on the quality of their services via this method?

Luebking: They were kind of surprised at some of the comments that they got. I think part of it is that success kind of feeds on itself, and so by showing that there was some concern, then we got more people involved, and as more people got involved, then it became a higher concern at Alta Bates. I think having them simply realize that they really are not doing as good a job as they thought they may have been doing or that it was more critical than they thought. If people don't know who to complain to, they're not going to take the effort, in many cases, to track that person down. And so that actually serves as a barrier for influencing change to the hospital. By using the Internet, e-mail, website, we were having a greater impression on the hospital of this being critical.

It still was not enough, though, because part of the problem was that the woman I was dealing with was going to be retiring fairly soon, so the impact really came forward when I talked to the new manager of imaging.

Breslin: What was that person's name?

Luebking: Rick Kaluza [Pause]. I talked about some of the problems I had with imaging and got a letter from him about the way it should be treated, and then sort of used that as a basis for beginning to generalize, and then was able to take that experience back to the disabled mailing list, letting them know about this. Again, the mailing list was being served as a conduit. There was this concept of community memory, and so my experience became part of the community memory in a much rapid period of time than would have occurred without the technology.

Breslin: What's been the sort of midterm impact of your work with Alta Bates?

Luebking: I think one significant piece was it gained them more focused on getting lift equipment for x-ray imaging and, through that, showing that the community is concerned about the way they are treated and also is willing to work with the hospital in order to achieve mutually satisfiable goals. I think that's a healthful approach, where cooperation that the community would know about display issues but may not be up on imaging issues, and that the hospital might be more aware of imaging issues but not up on disability issues. So by being able to create a mechanism for the two groups to share information, I think the results are going to be more positive.

One example is that an initial lift that was being considered came from the disabled community, but the imaging had heard of a different lift and wondered about that. So then the community was able to respond back to that and evaluate it that it be a preferred lift. Again, shared information that the disabled community would be less likely to touch on the lifts that are used in imaging departments in the Bay Area and that the imaging department would be less likely to understand how the lifts are going to be used by disabled people.

Breslin: When you say lift, you mean a mechanical lift that would enable workers at the hospital to move people from a wheelchair.

Luebking: Onto an x-ray table.

Breslin: Okay. But moving out of the abstract just a little bit, you're the one who set up the appointments, made the dates, contacted the lift manufactures' representatives, got people to come to test the lifts, and you're the one who facilitated the entire process. Isn't that so?

Luebking: Well, yes, but I think, again, the technology made it much easier for me to do it, and so being able to leverage off the technology meant that I really didn't have to put that much effort into it. For example, one concept that I have for the mailing list is an "online shout."

Breslin: Shout?

Luebking: Right, shout.

Breslin: S-h-o-u-t.

Luebking: Right. So basically, imagine if you were in a room and you shouted, "Hey, I need something." You have all these people who can come around and help you. So the mailing list serves as an online shout, where I can say, "Hey, Alta Bates is thinking of a lift and is looking for people to come try it, who's interested in trying it?" So the concept of an online shout really made my life much easier, so I didn't have to contact a whole bunch of different people asking them whether they'd be interested or not. But some people were interested, and then they told other people because then you had not only shout but you had ricocheting shouts that friends tell their friends, and so within a very short period of time, by using technology, you're able to reach hundreds of people and identify people who would be interested in it, so that's why it took very little time.

Sometimes I feel a little bit guilty because people look at how much effort it is. It's really not that much effort. It's that I have a little tool set up that makes it much more efficient for me.

Role as an innovator who opens doors to possibilities

Breslin: How do you think the disability community locally perceives you?

Luebking: Historically, I think I've received a lot of credit for the work I did at CTP, though I think also it served—CTP introduced the ideas of that I would be more of an independent thinker and not necessarily willing to go along with the crowd, just to be with the crowd but only if it made sense because of some of the ways that CIL was handling projects and things like that. Fortunately, we did some things with CTP which wasn't being done with the other projects, and we avoided some trouble for that reason.

I think for a long period of time, people saw me as being just a programmer, but they really didn't know what it was I did, so they couldn't characterize how what I was able to do would impact them. Really, at that point in time, technologically there wouldn't be that much impact because the technology I was working with tended to be a little bit more specialized, a little bit more sophisticated, something along those lines.

Breslin: How about now?

Luebking: I think that there were people who want to put me into very specific boxes, so they want to think about me as being technology. But then I do stuff like with the attendant referral, attendant issues, or do something with voting equipment or health and access issues, and so it makes it a little bit hard for them to actually put me in a box for that. But if I were to come up with a box, it would be a very big box, and it would be basically creative solutions to problems, would be the underlying theme that probably joins most of what I've done.

In a way, it reminds me of when I was in college, and my college adviser would look at the classes I'm taking and seeing how they were unrelated to each other and that there was no pattern, because I did stuff in computers, math, and psychology and theater, and I could switch between areas. I didn't differentiate in the same way. I think the same thing is true. I don't differentiate. They're just examples of different types of problems.

I think some people have seen me as being very conservative in ways, and there's other people that see me as being very liberal in ways. But I think it goes back to that they have to say whether I'm conservative or liberal, whereas I think what it really is that in each question, I more likely look at the question in itself rather than a particular label. And I think that's sometimes frustrating for people, where they want to have it not as multidimensional in looking at things.

I know sometimes people are surprised because I can do both technology, but also part of my background—I've had some background in psych and counseling, and so I can switch between those fairly easily. I think they're kind of surprised when I do that.

I've been told I don't talk about myself as much, and sometimes people think there's kind of this mystery around me. I've usually told people that they can ask me, but the statement that's come back is that I don't give enough information for them to know what to ask. I think there's some feeling like I'm wanting to maintain this mystery as much as—part of it is that sometimes when I talk to people, I can kind of confuse them because I can go abstract very easily, again because I don't differentiate the same lines that other people do. They may not see similarities in ways that I see similarities.

So, whereas I think the ability to think in similarities has been useful for coming with innovation solutions to problems, I think it serves as a barrier sometimes in being able to explain those solutions.

Is that kind of what you were looking for?

Breslin: It is. You need to say what you think the response is to the question. I'm also interested in whether you perceive yourself in a leadership role in the community, which is a slightly different angle on the way you've been responding to the questions so far.

Luebking: I guess I don't see myself as being a leader, but I don't see myself as being a follower, either. [Pause] I say innovator. I'm more likely to be an innovator. I actually talked with someone just today about how often my experiences have ended up as in an advisory, consulting capacity for the leader of an organization. I've seen that both on campus, in companies where I've often become the adviser for a CEO or a senior vice president or department chair or something like that.

And I think I end up in that position because—[pause.] Again, it goes back to I think I'm fairly comfortable with having an amorphous, undefined position, and people want to put me as a leader or something like that. I don't necessarily have that need for that label. I think I'm a little bit reluctant to look at it in those terms because I'm not sure I'm very good at leading groups of people.

Maybe another role I'm better at is opening doors to possibilities. I think something that is a little easier for me is to see that the door is there to the possibility.

— 140 —

Public service announcements for attendants

Breslin: Fair enough. Okay. I'd like to actually at this point ask you—

Luebking: What about the attendant stuff?

Breslin: We did. We did it in a previous interview, at some length, so we've already covered it. Good thinking, though.

Luebking: I didn't know whether we talked about PSAs [public service announcements] or not.

Breslin: We didn't talk about the PSAs, actually; we talked about the rest of it, the setting up of mailing list and the coordination functions. Say about the PSAs. Tell us what that is about.

Luebking: We were working with them, trying to do outreach to the general population about attendant work, and so we were interested in using PSAs in television in a humorous, innovative approach. We were able to hook up with the people who developed the "Got Milk?" commercials and came up with some very clever PSAs. They did just a great job: original and they did it for free, and high quality. In fact, the PSAs just got the Grand Festival Award for PSAs at this year's Berkeley Video Film Festival.

I've also used the PSAs in my teaching at the optometry school, as a way to break away from seeing disability as being a serious issue. It's something that can be talked about a little bit more light-heartedly.

Breslin: Are the PSAs actually being used as PSAs yet?

Luebking: We're having problems with getting them on the television at this point. We did some general meetings, but we're realizing that we might have to be much more aggressive.

Breslin: In terms of executing the PSA idea, you were responsible for thinking about the idea to begin with and for generating the contacts that made it be possible. Isn't that right?

Luebking: There was a group of us that were working on it. I can't remember exactly how the idea of the PSA came into play. I think it was initially introduced, and then someone knew someone who knew someone, and they were being brought in, and they knew someone, so it kind of expanded from there. And then it was like there were a couple of us who were kind of taking the lead on the whole thing. I was the technical adviser on the shoot sites for the disability stuff, kind of serving as a go-between, between the organization and the people who were doing the PSAs. But different people brought in different skills in the process.

Breslin: Anything else on that?

Luebking: No, I don't think so.

Reflections on diversity in the disability movement

Breslin: Okay. I'd like to just talk a little bit, in sort of broad terms, about the disability community and the disability movement from your perspective, just by way of wrapping up. There are a number of kind of obvious issues that any observer of the movement would be aware of. For example, there appears to be an absence of minority individuals involved in the movement at pretty much many levels. The role of women in the movement has been noted by a number of people. I'm wondering on those two questions, do you have thoughts or observations or reflections or what is your take on those two issues?

Luebking: In terms of the minority issue, what kind of comes to mind—there might be several aspects to it, but one of the things might be that in order to become active in the disabled world, you have to have resolved a lot of your own disability issues, so it's like a two-tier approach. First you have to take care of your own needs, so that requires, especially for the more severely disabled, a certain amount of skill, background, resources. And then I think, looking at the spinal-cord-injured, quadriplegic population, that for a lot of people, if they're middle-class white males, they're going to be coming in with experiences and resources which they'll be able to bring into play for handling their disability. I think that's going to make it a little bit easier for them to become active.

If you're a disabled person without that experience, it's going to be much harder for you to become stabilized in dealing with your own disability issues. So I think there's that aspect of it. For example, when I became disabled, even though I ended up in a hospital or rehab institute before, I had a sense of how it would work because I had known how other institutions, such as schools, colleges, whatever, would work, so I was able to bring that experience into play of who to talk to.

I understood the difference between formal communication structures and informal communication structures, how to get my needs met by helping the organization get their needs met. Things like this that I had learned.

Breslin: This is your institutional knowledge as a person who's been learning throughout their life in school and through various exposures at sort of a class level.

Luebking: Yes. So I think there is that piece of it. Also with being a middle-class white male, I didn't have to worry about the other issues; not being a minority, so I could focus more of my energy in that one area. Whereas if someone is a minority and also disabled, then they have to deal with putting energy into both areas, and so they may not be able to accomplish as much. It's going to take a great burden on their energy.

There might be an issue, again, being a middle-class white male, of a belief that if I put my mind to it, then it's what will happen and that it may take a while. I may have to work at it, but there is a confidence that something will happen.

Breslin: Is that a confidence that you have, that you have control over your world, your environment, or your destiny?

Luebking: I'm not sure I would say I had control as much as I have impact. Control would be where I could pretty much get done what I want to do, whereas with impact, it's like I can head it in the right direction. It may not be exactly what I want, but the outcome would be closer than if I hadn't done anything. It's that sense of it. Someone in college, after my injury, said that I remind them of a cork, that no matter how far down I was pushed, I would always come back to the surface. I think there's that aspect somehow that comes into play.

Breslin: Do you think that has to do with where your primary identity lies, as a white male, as compared with the primary identity, say, of a person of color?

Luebking: I don't think my primary identity is really a white male. [pause] It would actually seem to be a sense of intuition and experience that was not impeded, being a white male. For example, writers or musicians talk about being on the beam, and they just know that the writing is right or they know that their composing is right.

Breslin: They're in the groove.

Luebking: They're in the groove. I had always had an ability to be in the groove, and I don't know how that works. It's just like it flows somehow, and that's more according to my nature.

Breslin: Stepping back a little bit from your personal experience, some people have suggested that the fact that there are few minority activists in the movement is a function of identity more with issues of race than with issues of disability. Does that resonate with you as an explanation, or not?

Luebking: I can see it in a different variety of ways. For example, if you're talking about, let's say, a black man whose image of himself as being successful is based on being physically active and that's part of culture—racial culture, something along those lines, that by having that removed from them, their identity is being significantly negatively impacted. So there might be that aspect of it. It's the interplay between the two.

There might be also a feeling of how they form camaraderie with their environment, and it might be more based on people that they know locally, in their area, and so they may not be able to organize in a non-local fashion. So there might be that aspect of it, also.

There might be an aspect of why try anything because they're not going to be successful because they haven't been successful in other ways of their life.

Breslin: I think the proposition has to do with perceiving race issues as more relevant than disability issues for personal commitment or for taking action or for involvement. Does that make any sense to you, or does that seem like a plausible explanation?

Luebking: In a way, it is interesting. I haven't heard as much of people arguing that a person should be called a person who's black versus a black person, whereas I've seen more people arguing that a person should be called not a disabled person but a person with a disability. So the issue of identity coming in there makes sense.

The other thing is that—my sense is that a lot of disabled people in the black community or in racial minority groups are pretty isolated, so they don't know a lot of

each other. And so to identify with a couple of people outside their experience may not be that easy for them, whereas their friends, their family and all—they're going to have an easier time identifying with them.

Issues of shared experiences as being limited within society can be a strong, binding influence, but also whether there's—it would be kind of interesting to see how the differences for someone who is disabled [inaudible], disabled within a minority group versus someone who became disabled later on, and how that might impact their activities.

Another issue to ask is could this be a consequence of the state of health within racial minority groups. For example, if you're a white disabled person, are you more likely to survive than versus a group from a racial minority? And so is that one of the reasons? Or are you more likely to be healthy? And so the consequences of their identity and their health might be working in some subtle ways.

I'm not sure I'm answering your question.

Discussion of women's leadership in early disability movement

Breslin: There's not a right or wrong answer. We're interested in people's views on what you think about the topic. There's been a fair amount of criticism lodged against the movement as a whole for not reaching out and being more aware of and proactive about diversity within the leadership and within the rank and file, so that observation, also that criticism is what generates the interest in people's views about why that might be true and why the predominance of people in the movement tend to be white.

Let's actually reflect a little bit, or let me ask you to reflect a little bit on the role of women in the movement. It's been said by many that the majority of the movement leaders, at least the early leaders, have been women. I guess we have to decide whether that's true or not, but that's the contention of many. Is that your observation? If it is, why do you think that's true? If it's not, why do you think it's not true?

Luebking: [long pause.] I think to some degree it's true. I'm not sure how to quantify that. I think that part of it might be—I could be wrong about this, but there is a correlation between disability and concepts of nurturing and that men may not be as attracted to issues of nurturing, and that might come into play in some way.

I think there also might be a transference of skills from women's liberation and needing to fight for what's out there, and so there might be some skills have been developed, whereas guys may not have had that experience.

One of the things that comes to mind is that within the disabled world, it's been harder to maintain a gay man's disabled support group, meeting place or whatever, and it's been much easier for the lesbian community to support disability issues. I think that there is some factor that's coming into play there. If you look at events which are done by lesbians as compared to gay men, I'd say in general that there's more accessibility at lesbian events than there are at gay men's events.

Breslin: When you say accessibility, do you mean literally?

Luebking: Yes, literally.

Breslin: Architectural accessibility.

Luebking: For disability.

Breslin: Or openness to disability.

Luebking: Yes, program access or whatever. I think that again goes back to the idea of nurturing, stepping outside of what your needs are to see someone else's needs.

Another possibility is because of lack of interest of men in the issue, as someone being seen as nurturing or whatever, that there's been a vacuum of leadership that has allowed the women to expand into it, and that if people—I think a lot of disabled men are ambivalent about their disabilities because it might tie into the issue of not wanting to be seen as being passive or weak or whatever, so why focus on some stuff that will let them move out of their awareness of the disability, whereas women might feel more comfortable in terms of being disabled because of cultural images that are presented.

That may serve as a basis for them to move past that, so initially they're comfortable with it but they're not too comfortable, but they were comfortable enough to allow growth, and that disabled men might not have that same option, because I think a lot of them first think of themselves as men, with whatever is encumbered on them by society.

The ebb and flow of the disability movement in Berkeley over the last thirty years

Breslin: Okay. You've been an observer as well as a participant in the sort of Berkeley wing of the disability movement, on and off for practically thirty years. Can you just reflect a little bit on, step back a little and reflect on the impact of the Berkeley world on the larger disability movement?

Luebking: I think, of course, back in the sixties there was much greater impact than there is recently. I think the first thing is that they served as a basis of setting up the independent living centers, showing what was possible, that they started breaking down concepts, beliefs. I think Berkeley was at the right time, the right place. It was after the sixties, but there was still a lot of feeling about expanding past what society had laid out, so a group that is willing to challenge that would be supported in Berkeley.

But I think also an aspect that was different was that if the University was not here, would that have been enough? And I think that the University served as a major screening factor for bringing in very bright, disabled people, giving them protection and nurturance and letting them grow, and serve as a basis for a lot of the new ideas for the new ways of looking at things, and in that way serving as models for other places in the country and other places in the world.

I think it also really didn't present people—it fosters some false beliefs in disabled people that—they went very far the other extreme, saying that disabled people were competent in doing a variety of things, whereas what should have been a better model and one I always tend to go for is the importance of cooperation, where different people bring different knowledge and different abilities and ideas to figure out how to integrate the people to approach problems.

The model more in the seventies was that if you were disabled, you had the background to do whatever you wanted to do, and so for that reason, people were given positions that they were less effective in, merely because they were disabled, rather than being nondisabled. I think that was not as well recognized. I think if that had been earlier recognized, that you need to have a blend of skills and knowledge, that some of the mistakes that were made and some of the energy that had to be used to take care of the mistakes could have been better used to reach out and to serve as a stronger basis for activities.

Whether the 504 demonstration would have occurred as well in other locations, I'm not really sure about that. I think if you look at the other demonstrations that were happening that first day, they basically faded, and [inaudible] the demonstrations in the Bay Area, primarily out of Berkeley, was the reason that existed, and it showed that, again, a challenge to various ideas that people had about what disabled people can do and what they were able to successfully accomplish.

Breslin: You had said in an earlier interview that you didn't understand why the concept of independent living and particularly a CIL-type organization hadn't developed before it developed here—you said you didn't understand why that was the case. But it sounds like you're actually explaining why it possibly didn't develop earlier. Have you reconciled that issue in your own mind?

Luebking: [very long pause.] I don't think so. I think what it is—[long pause]—no, I really haven't. I'm not even sure how to reconcile it. That's a very good question. I really haven't thought about that. Both I see very clearly.

Breslin: The reason the question is important, I think, is because the movement is old enough now, and there's a great deal of interest in trying to understand why did it happen when it happened? Were there factors that can be quantified? Were there circumstances that were particularly unique? Why was the sixties and early seventies the pivotal time period when it all began to really develop, both here and elsewhere? I think as historians try to unravel the question, they'll benefit from whatever your insights and the movement's insights are now. And I don't think we know the answers; I just think we're trying to think about what was going on and maybe offer up some observations. That's about the best we could do at this point. I don't think you have to reconcile it, but your insights are helpful.

Luebking: I think that in a way, when I look at the world, I look at the world through different filters. That's why I like to be exposed to a lot of pieces of information. Different filters accentuate certain aspects that other filters don't, and they also diminish other aspects

that some other filters will enhance. For me, it's just changing filters. And I think that the two filters I'm using would be the difference in personal experience versus social processes. What I mean by that is looking at people who have been able to be pretty independent, no matter where they live, versus other people who need more support.

I guess I haven't quite resolved that. It might be, again, the difference between the sense of how much impact can you have on your life versus how much impact society has on your life.

Breslin: If you have 10 percent control over impact and society has 90 percent, then the chances of a social movement forming are less, perhaps, than if you have 50 percent and society has 50 percent.

Luebking: I would agree with that. I think there are arguments—I'm not sure if I've mentioned this. One time, in this interview by the *Chicago Tribune*, and at one point in the article they said, "To Scott, the word 'no' means 'find another way.'" And I think there's that part of me that comes from that place, because I'm very problem-solving-oriented, so if there's a problem and I'm not coming up with a solution, then I'll figure out another way of doing that. I think, looking at that filter, when I see people interacting with problems, it's a matter of figuring out a way around the problem.

I think it also might be somewhat reflective of my not viewing myself as a leader and having impact on leading groups of people. I may not think quite in those terms. It might also be how tying this to my frustration is that what I'm seeing in the current disabled population, at least in Berkeley, as being much more passive and reluctant to put energy out to doing stuff. Unless they become active, things aren't going to be accomplished.

Really, it's offering me some insight into myself that I haven't really thought about, because I have a strong awareness of the concept of [Regina Satira?] on power structures and a person being within the context of the family, which would fit more with the social model issue, that you have to look at your interaction, how it's going to impact the rest of society, that could hold you back from accomplishing something.

There's not a lot I can reconcile, though. I think what it is, it's one way of looking at the situation—again, what filter I'm using.

Personal goals for the movement's future: recover lost ground, quality of life, health care access, technology

Breslin: Okay. Well, I think it's a complicated question. All insights are valuable, and will be valuable particularly later, as people go back and try to look at what we were thinking about, our own times, in a later time.

Shall we move on to—this is sort of the last generic question, and it's more asking pretty much everybody we're interviewing, to reflect a little bit about the future and

where you see the disability movement going and what your own personal goals would be for the movement, looking ahead.

Luebking: I think one of the short-term goals is how do we recover the ground that's been lost, and how to prevent even more ground from being lost.

Breslin: What do you mean when you say lost ground?

Luebking: I think some of the judgments that are coming out of the Supreme Court would be one example—actually, a very strong example, both in terms of the actual decisions, but also it's beginning to introduce into society a certain acceptance of denying disabled people, whereas before, the people might be willing to deny in some way disabled people; they would be apologetic about it for some reason or something like that. And I'm wondering whether the Supreme Court activities in a way is allowing it to be more socially acceptable to do that. Whether that's actually true or not, I'm not sure, but it does kind of come to mind. I really don't have a sense about whether this is just a blip or whether this is the beginning of reversal of people's attitudes.

I'd say definitely there needs to be prevention of loss of ground and recovery of what has been lost as the first step. I think that the issue of equality will always be one of—will never be totally understood, because there are so many dimensions of equality that doesn't exist for other minority groups. A black person doesn't need any significantly different architectural needs than a white person for getting into a building or something like that, so equality is a little bit easier to determine in that case.

But if you have someone who is in an iron lung, how do you handle equality in that case, and what exactly is equality, and what perspectives will be brought to bear for evaluating that?

Fundamentally, I don't think that will be ever answered. Then the question becomes how do you choose the degree of acceptance of inequality, what is fair. That also may a question that may not be easily resolved.

So when you have these two unresolved questions, it's going to be much harder to come up with a firm basis for making some of these decisions, which means that then there are going to have to be greater impact in terms of influencing society for the values that are going to be in play because the values have a hard time being rationally justified.

Am I being very clear about that, or should I talk more about it?

Breslin: I think what you're talking about are the differences between what some have called structural or formal equality versus the idea of material equality. They talk about it in the context of human rights versus civil rights or anti-discrimination rights. What you've touched on is the huge debate that's going on worldwide about distribution of wealth and access to equality in the most fundamental sense of food and housing and shelter and safety versus opportunity to participate in the community, in society. So I think they are extremely fundamental issues, and you come at them not so much from a law perspective but from an observational perspective, I think.

Luebking: Yes.

Breslin: So they're especially important in the sense that you're not practicing in an area where it's being talked about a lot, but observing them, which is an interesting contribution, I think.

Luebking: I'm just not sure whether there would be any ways to come up with satisfactory answers, because as soon as you have limited resources, then you have the problem of how you distribute the resources and how do people choose to value people, how you're going to influence that.

Breslin: Those are really critical macro issues. Are there subject-matter issues which you see as the most important, say, two or three that might be facing the movement? We've mentioned the Supreme Court setbacks. Is there anything else that comes to mind?

Luebking: I think quality-of-life issues; again, access to health care. I think the access to health care impinges on disabled people even more, as there has been a retreat in the amount of health care that's available for people. The disabled people are going to be out of proportion affected. Of course, that's going to affect the amount of energy that disabled people have for addressing these other issues.

I think another issue of the quality of health—quality of life—is going to be access to the financial resources and support. Again, that ties into jobs and the whole thing. They're all intertwined. That's why I say the quality-of-life issues, access to education—[long pause].

Breslin: In light of the successes of the movement—you agree that there have been some—are you optimistic for the future?

Luebking: [long pause.] I'm not sure I look at it as optimistic or non-optimistic. I think I look at it in terms of some aspects may be optimistic and some aspects may not be optimistic. Intuitively—again, I could be wrong about this—but something tells me that looking at the success of the Olmstead Law, looking at the success of the implementation of solutions for Olmstead could be like a bellwether to see how a lot of things might be addressed.

Breslin: Just explain what Olmstead is.

Luebking: Keeping disabled people in the least restrictive environments. That touches on a lot of different areas. It's pretty clear that society, without the force, encouragement, whatever, energy of the disabled world, is not going to move rapidly in the direction of implementing Olmstead for disabled people being in the least restrictive environments, so it's going to fall back to the disabled community to keep that pressure going in the right direction. If they're successful, again, success will lead to success and might show that they're recovering some of the power that they may have lost at this point. However, if they're not successful with getting Olmstead implemented, I think it will help to convey the idea that disabled people are politically weak, and make other things even harder.

I think another thing would be fixing the holes in ADA and revising it, seeing it in ways that have been very successful in terms of access to buildings and things like that, but in terms of jobs and all, it's not clear how successful it's been in that area, so why hasn't it been successful and what needs to be changed for that to occur?

I think that the disabled population has very little impact in terms of where the direction of technology is going. I'm not sure what needs to be done with that. I think the quality-of-life issues need to be addressed first, and that will give them a stronger foothold for influencing changes in the directions in technology.

Breslin: Do you think they're interrelated?

Luebking: Yes, I think it's a chicken-and-an-egg aspect of it, that improved technology would improve the quality of life, and the quality of life will of course give them more influence on the technology.

Breslin: Okay, good. Any other final reflections that you'd like to make before we end?

Luebking: [sighs.] There is part of me that really strongly believes that disabled people need to take control and have impact. That sounds rather naïve and simplistic, but without that, the more passive the disabled population becomes because of age, being burned out and all, the less successful they're going to be in maintaining what they have and making progress.

Breslin: Are you hopeful that the new generation is coming up to take charge, which would solve some of that problem.

Luebking: I'm not really seeing it, but they might be bringing in other skills and other ways of influencing which might be more subtle and harder to detect except by looking at it over a period of time. But I'm not sure about it. Again, going back to Berkeley, it was the right time, the right place, the right people. Was it by chance?

Breslin: Random? Just a random collection of factors?

Luebking: Well, it's a random collection of factors all becoming active at the same time. I'd feel better if Berkeley had been replicated in other places to the same degree. I'm just not sure about that.

Breslin: Okay. Any final words?

Luebking: No, I don't think so.

Breslin: Okay. Thank you.

Spinal injury and rehab, 1970

[Minidisc 6]

Breslin: This is Mary Lou Breslin. I'm continuing with Scott Luebking on November 26, 2002.

— 150 —

Okay. So, Scott, let's talk about your decision to go to Knox College toward the end of high school or whenever you made the decision. What prompted you to decide to go to Knox?

Luebking: I wanted to go to a small college for undergraduate, because I didn't think I was emotionally mature to handle a large place, and I thought I would do is go to a small private school for undergrad and then for graduate school go to a more better-known university. I wanted a place that didn't have an English requirement because I had problems with English, and Knox didn't have an English requirement and Knox had a reputation of having a very good math department.

Breslin: So it was a good fit.

Luebking: Yes. And it was close enough to Chicago that if anything—if I needed to get home for any reason, I could get home [inaudible] couldn't just have my [inaudible] dropping in and visit me.

Breslin: That was the incentive?

Luebking: A little bit, yes.

Breslin: It was after you had been attending Knox for a while that you had your accident. Is that right?

Luebking: Yes, it was after my freshman year.

Breslin: What happened?

Luebking: I was working up in a camp, and had a diving accident when I was playing a game in the water with the kids.

Breslin: What happened after the accident?

Luebking: I made a dive, and I wasn't paying enough attention to the dive; I was paying attention to the kids, and I hit the bottom of the lake and crushed the vertebrae in my neck.

Breslin: Did you go into a hospital locally, or what happened after the accident?

Luebking: They pulled me out of the water, and then they called the ambulance and I was taken to a local hospital.

Breslin: And from there into a rehab program?

Luebking: I was there for a week, and then they brought me back near Chicago, and then I had surgery. I was in the hospital for about four weeks after my surgery.

Breslin: Was this a hospital in Chicago?

Luebking: Actually, Blue Island. And then I was transferred to Rehab Institute of Chicago.

Breslin: When was this?

Luebking: In late September.

Breslin: And what year was it?

Luebking: 1970.

Breslin: Can you say a little bit about how your experience was at the Rehab Institute?

Luebking: I think the thing I got a little bit shocked was up until that point, people were talking about recovery and how it takes some people a while, and stuff like that, and how they don't know the extent of injury for a long time. Then when I got to rehab I met people who had been going there for, like, a couple of years and I started seeing that there's a lot of situations where people don't recover. That was one of the first things that was kind of shocking.

Breslin: Who was telling you that you were likely to recover?

Luebking: They didn't know. They would talk about other cases of people who recovered.

Breslin: I see.

Luebking: At that point, I had been reading *One Flew Over the Cuckoo's Nest*, and, like, the week before I had just actually gotten to the point of reading the part about the dream, where people are hanging from the ceiling and stuff, and then, like, a couple of days after that went to physical therapy for the first time, and they had people hanging from the ceiling.

Breslin: Oh!

Luebking: As part of therapy, which was kind of a shock. And so I mentioned that to one of the therapists, and she told my doctor. Came down, took my book and gave me *Sometimes a Great Notion* instead.

Breslin: [laughs.]. I don't know if that's any better, actually.

So do you remember how you were thinking about your disability at that point?

Luebking: I still didn't know how long it was going to, whether it was permanent or what was going on, but I had heard that they were going to see *2001*, the movie, as one of the recreational trips. When you were going on a recreational trip, you had to have five hours' seating tolerance, and I had been flat on my back for about six weeks or so, so I said, "Okay, I really want to go, so I'll try to get my seating tolerance." They put me on a tilt table which was free standing. Normally, they raise it up a few degrees each day and they get you more upright, and by the second day I was pretty much upright, almost fainting but hanging in there.

And then over the weekend I was able to be up in the chair and not passing out, and so within a week—it wasn't that; five days, I think, something like that—I was able to go to see *2001*. They said I almost set a record, or something like that. I did it really fast. But it was just being able to be really focused. That's what I wanted to do.

Breslin: It's such a profound physical thing that happens with that kind of an injury. Did you go through some period of major adjustment, or did you just take it as though it were kind of an everyday event?

Luebking: I think I became more sensitive to the issue of being trapped, and that had an impact on me. I had always been a problem solver, so it presented me with a series of new problems to look at. I think feeling more dependent upon people had me nervous because that was one of my better skills, was interacting with people. I think being afraid to go out and having to interact with people had me nervous.

Breslin: Did the sense of being trapped have to do with being physically trapped?

Luebking: Yes.

Breslin: Was that the worst of it in terms of, like, your immediate response? Was that the worst thing that happened, or the hardest thing that happened?

Luebking: Nothing I would do worked the way it used to. It was very frustrating. I think that kind of fed into the sense of being trapped. Not being able to go out into the woods and stuff like that, like I used to, was frustrating. [pause] I think there was a sense of not knowing how to interact with the staff, because I was being exposed to people I wasn't familiar with before, so I was very analytical and very logical about stuff. They kind of felt that I had magical powers or something like that, because I was very focused on using my mind to solve the problems. When I heard that, that just didn't make sense to me.

Breslin: Wait—the staff thought you did?

Luebking: Yes.

Breslin: Really?

Luebking: Yes. It was very strange. I didn't find it out till—

Breslin: There's a progressive viewpoint by the medical profession!

Luebking: Yes.

Breslin: [laughs.]

Luebking: Yes, they believed I had magical powers or something. I said, "No, it's just logical." And I had problems with—they wanted me on the floor at eight o'clock, and I would want to be reading or something like that, so I would show up at eleven o'clock, and they'd be upset by that, so we had this continual war about stuff like that.

Breslin: Were you thinking about what was going to happen next, when you were in rehab?

Luebking: I was pretty sure I would want to go back to college, and I had a scholarship that would be held for me, allowing me to go back to college. That solved a lot of problems also.

Breslin: It didn't occur to you that there might be a problem for you, going back to college at that stage?

Luebking: Well, they had been building a new science building that had to be made accessible because of the funding that they got, so I was very lucky with the timing, that when I would go back was just when the new building was opening. In the science building, they were going to have math, which was my major. They had the computer section, and they also had psychology. So my main areas were going to be in the new, accessible building, and so I was very lucky that way. And my other interests were in theater and art, and that building had been accessible also.

I got a lot of my requirements done my freshman year. I still had a couple, like social science, so they switched the social sciences to the science building, so I could take those classes. So, again, having gone there, they kind of knew me, and that made things a little bit easier.

Breslin: I was just wondering if you were thinking about any of that when you were in rehab, because it wasn't necessarily completely self-evident that it would work out that well. Or maybe you knew, kind of in advance, that it was going to be okay.

Luebking: I think the thing that had me most concerned was dealing with the attendants, how to get attendants in that area.

Breslin: How long were you in rehab?

Luebking: About six months, from late September to late March.

Breslin: Did you go directly back to school from rehab?

Luebking: Yes.

Breslin: No break, no period of time at home?

Luebking: No, I just left rehab on Saturday morning and went directly back to my dorm.

Breslin: [Laughs.] And were you using a manual wheelchair?

Luebking: No, I had an electric. It was one of those where the motors would clamp on the back of the chair.

Breslin: Ah—Motorette.

Luebking: Right, it was a Motorette. The campus was fairly small, so it worked out fine. And then I knew it wasn't going to work for snow so that's when a got an E & J [Everest & Jennings wheelchair] for winter.

— 154 —

I think one of the other things with rehab was—the sense of loss I had was, again, tied to the issue of freedom for me—freedom and independence. That was one of the main things. But when I compare myself to the other people and their experiences, what I saw was their identity was much more crushed, in ways. Like, they were having to rethink who they were at a core level and that their value was based on their relationship to the family, jobs, and stuff like that. I didn't have that experience.

Breslin: So your core identity was not challenged by the new circumstances.

Luebking: It wasn't based on the things that got changed, so it was a lot of trying to, again, solving a lot of problems, but I think being able to pretty quickly get myself to a level of function where I could go to a movie within a few days of being in rehab was probably useful, that I would understand, I could learn, I could take previous skills I had and apply them to new situations.

I think I had some fear of being trapped, and at times I think I would get depressed about that, because I knew of other people that would leave and would go and be forced to spend days and weeks in bedrooms or apartments that they couldn't get out of, and that bothered me a lot. I was afraid that would happen. At an emotional level, I think I probably knew that that wouldn't happen, but I just was never sure of that.

I think another aspect is part of the independence arose from not being comfortable interacting with people, so I kind of developed stronger independence skills to compensate for the problems I had interacting with people. That was a challenge.

Breslin: Who was your doctor?

Luebking: My primary doctor was Jane Borges, and then another one was Henry Betz, and there were a couple of others.

Breslin: Do you have memories of Henry Betz?

Luebking: [laughing] Yeah! Yeah.

Breslin: I see. [laughs.]

Luebking: He was known for being sort of pompous and arrogant, but very skilled. But my doctor did get along with him, so that helped us to get along.

Breslin: Did you have to deal with him personally?

Luebking: Yes, on a few occasions. Basically he was at the backup for when Dr. Borges was away.

Breslin: What did you think of him in terms of your relationships?

Luebking: Well, he needed help with learning to listen, because he was pretty convinced he knew what was best, and having a college freshman question him did not go over very well, and I could be very direct in my questions, so it was not a match made in heaven. Again, we only had to interact for short periods of time. I'm not even sure he would remember me. He'd probably remember my name, maybe.

— 155 —

Return to Knox College

Breslin: So you go back to college. Did you have to prepare in advance to deal with any of the accessibility or attendant care or disability-related issues, or did you just plunge in and solve them when you got there?

Luebking: Oh, no, we had to make arrangements, get everything worked out ahead of time; otherwise, the school wasn't going to let me return. There's a hospital two blocks away, and they agreed to make arrangements for their orderlies coming by before and after the shifts to get me up or to put me in bed, which really didn't work out very well because, again, I did not like to live on a particular schedule. It was helpful because it served as bridging; it relieved the school of anxiety about what would happen and just knowing that medical professionals were involved. And then, once they saw that I was pretty stable and had very few health-related issues and seemed to show I could manage attendants, then that wasn't as much a concern.

The education—the math department ran interference for me for making sure that everything would work with the classes and all that, so I had the support of the Math department, which was really—with Dr.Young, who was my adviser, who was very helpful.

Breslin: Well, it sounds like it was a pretty smooth transition, under the circumstances.

Luebking: In ways, but also I had problems with wheelchairs breaking and lack of wheelchair maintenance. I had problems with catheters, and there was a lot of learning that I was going through: issues of not typing very fast. The ramp for the dining room was not complete, so I had to be carried up and down the stairs all the time.

Breslin: In your motorized chair?

Luebking: Yes. Again, I was lucky because it was a Motorette, so it was not that heavy.

Breslin: So how were you coping, as a practical matter, with wheelchair breakdowns and catheter issues and attendant issues?

Luebking: The wheelchair—people in the physics department helped me with maintaining the wheelchair.

Breslin: In the physics department?

Luebking: Yes, because people could do welding and stuff like that.

Breslin: [Laughs.] Thank God for science guys!

Luebking: Yes. And then they gave me a carrel in the library, so I could keep most of my books and all that there, so I didn't have to carry stuff back and forth.

The catheter just kind of—because I had dealt with catheters while I was in rehab, but I wasn't as active. Being more active, I had more problems with catheters, but I got that resolved.

Again, the feeling of trapped, that there were a lot of places I couldn't go on campus. Like, there was only one dorm that I could be in, and I couldn't go into the old library, which I liked a lot, which was okay because the materials I needed were in the science library, and that was where my carrel was at, so that was much easier.

Breslin: Were there other disabled students on campus?

Luebking: No, I was the first one they ever had permanently in a wheelchair before, much less a quadriplegic, so it was a significant leap for them.

Breslin: It sounds like they tried to meet you pretty much halfway.

Luebking: Yes.

Breslin: Responding to your individual needs, at least. They didn't necessarily see this as a broad issue.

Luebking: There were some things. They wanted me to pay for the ramps.

Breslin: Ooh!

Luebking: So the math department heard about that, and that was taken care of. Again, just the right people who were very vocal. And then the group of friends that I had made before were incredibly helpful. They were the ones that got me up and down the stairs, and dinner, always calling me to make sure I had meal access, and things like that, running errands for me, doing laundry. They and the math department played strong roles. Again, the math department, in protecting me from a lot of problems that were going on.

Breslin: How were you dealing with attendants after the arrangement with the hospital ended?

Luebking: I went to hiring students.

Breslin: Hiring students privately.

Luebking: Yes, which actually worked out a lot better.

Breslin: Did your disability interfere with your course interests or the direction you were taking in terms of your long-term career plans?

Luebking: No, I was pretty lucky. I had to learn to write again, and I was motivated to learn to write again because of math. It was hard doing math on a typewriter. I was using a splint for writing, which was a hassle. One time a professor was doing something long on the board, and I didn't have my splint with me, so that really motivated me to learn to write without a splint, so then I learned to do most of my writing without splints. As I say, math helped in that motivation.

— 157 —

Breslin: Any other incidences or anything else you'd like to recall in terms of your experience at Knox?

Luebking: A lot of people knew who I was just because I was an anomaly. I didn't know them. I was pretty active in a lot of different ways. Again, socially I was pretty limited just because the access of places and also being somewhat shy, in ways. But, as I say, in a lot of ways the community went out of its way to make sure I was participating in a lot of things. So I was active in theater and took acting classes and was responsible for [inaudible] and [publication boards]. I was head of the student judicial body and different things like that.

I think one of the hard parts was it was cold. It was very cold.

Breslin: Yes, that's how Illinois is.

Luebking: Yes. Again, it was out in western Illinois, so we had very bad chill factors. Then some friends helped me with learning to scuba dive, so I spent one of the quarters learning to scuba dive. The school was a little bit upset when they found out about that. It gave me an opportunity, though, to get to know the president of the school, because I had to meet with him on different issues, and so he learned more about my disability because of that.

Let's see what else. [pause] I think it being a small school, I was very lucky that way. That gave me a chance to know a variety of people.

I think, still, for me it was the right move, of doing the small, private school for undergrad, followed by a more well-known university for my graduate work.

Breslin: Were you thinking about where to go to graduate school toward the end of your stay at Knox?

Luebking: Yes. I wasn't sure where I wanted to go. I knew I wanted to go someplace that was good in computers, because just when I entered college, I seemed to have a native ability for that. Then I was reading the *Rehabilitation Gazette* that summer between my junior and senior year, and it was talking about Berkeley, and Berkeley was, like, one of the top three in computers. They had this residence program for disabled. That seemed to make the most sense for me, so I went and applied and got accepted.

It was kind of odd because what I didn't know was that they actually worked with disabled, to help them get accepted and all that stuff, and so when I called in saying, "I'm coming," they said, "Okay, what do you need us to do?" They said, "Do you need any help with getting accepted?" I said, "No, I've already done all that stuff." So I did know I could find help if I needed. And it was kind of like they didn't quite know how to handle that concept.

Breslin: You just needed the support services but not the academic part of it?

Luebking: Yes.

Breslin: So when you graduated from Knox, you went immediately to Berkeley?

Luebking: Yes. That's when I went to Europe, then came back and went to Berkeley. Graduation was pretty interesting.

Breslin: Why is that?

Luebking: Again, it was, like, having to deal with accessibility of stages and all that. They had designed it without wheelchairs in mind, so we had to figure out a way around that. They wanted to have me just pass in front of it, and I said, "No, if the students are going up, I want to go up." And then I got a standing ovation because I had graduated Phi Beta Kappa and magna cum laude. So that was interesting.

Breslin: So were you carried onto the stage?

Luebking: Yes, I was carried up the stairs on one side and carried down the other side.

Breslin: Were you at all thinking about kind of the broader disability issues in the world at this stage, or were you really just dealing with your own day-to-day needs?

Luebking: [Pause] I'm not sure how much I was dealing with disability issues, because a lot of stuff had been resolved. We had to figure out solutions to it, so most of my effort could be devoted to my studies.[Pause] I think the experience I had in high school and my freshman year in college of requesting and getting needs met helped me to become better at asking for my needs when I became disabled, so I think I came in with that background.

Breslin: Did you have a sense that there was a growing momentum toward a disability movement, at that stage?

Luebking: No, not really. Well, I know that they were trying to ship everybody off to the University of Illinois, and I knew that I didn't want to do that.

Breslin: Why not?

Luebking: Because I already knew the people at Knox. I felt, again, I wanted to go to a small, private place, and so Illinois wouldn't fit into that aspect for me.

Breslin: It was not because you were opposed to the program there? It wasn't because you didn't want to be involved in the U of I program?

Luebking: No. Well—

Breslin: The disability program.

Luebking: I had also heard that they didn't take quadriplegics. You had to provide your own care, and that wasn't me, either. But, more, it was that's where I had gone to school before, so that was the driving force behind it.

I think the other thing in dealing with Knox was realizing the degree to which things would be locked out for me because of the number of buildings on campus that were not accessible for me. But, again, they were buildings I probably wouldn't have gone into before my injury, anyway. I think, again, I experienced some sense of loss through that.

Breslin: A sense of potential loss, maybe.

Luebking: Yes.

Breslin: Like the choices are narrowed, even if you don't want to take advantage of them.

Luebking: Right.

Post-graduate tour of Europe; the power of public relations

Breslin: Tell me about going to Europe. Was that a vacation?

Luebking: Yes. I had heard about a program for disabled people to go to Europe, and so I contacted them and said, "I want to go, but I want to not necessarily be stuck on a tour all the time. I may want to do other stuff." I explained I was just out of college and was pretty young, and a lot of people that were going much older. Not all—a fair number. And so I thought for the first time going to Europe, it would make sense to go with somebody that knew the ropes, and so I decided to do it that way, rather than learning everything the hard way.

It was still kind of frustrating because I would have liked to have seen more castles and done a lot of other stuff, but I think for the first time, it was a nice tour.

Breslin: Where'd you go?

Luebking: Italy, Germany, Switzerland, France—the big four.

Breslin: Did you enjoy Italy?

Luebking: Yes. Actually, Paris was definitely my favorite city. I liked some parts of Germany also.

Breslin: Were you traveling with an attendant or friends?

Luebking: Yes, I was traveling with an attendant.

Breslin: Was that enough to get you where you wanted to go?

Luebking: Yes. His family lived in Rome, so he knew a lot of Europe.

Breslin: Oh, that's a great help

Luebking: Yes.

Breslin: So from Europe to UC Berkeley.

Luebking: Yes.

Breslin: Okay. Anything else about that period that you want to say before we end?

Luebking: Again, I think it was very fortunate having good friends that helped me to make the transition at Knox and having Dr. Young in the math department being behind me, because without them, that wouldn't have happened. Again, I just feel in ways lucky it was the right time. The building was just opening up. All the things seemed to be aligning. People who were in power at places of influence could pull strings to get things done. They were willing to take a chance on my leaving rehab and going directly back to school, and that my doctor was saying it was rather unheard of.

Breslin: Probably not "rather unheard of"—<u>not</u> heard of.

Luebking: Yes, she said it was rather rare, but I had consistently shown stubbornness and willingness to confront stuff and to come up with solutions and to not make really dumb moves, that people were willing to trust me to do the right things. I think it was all that kind of coming into play. In rehab, they were looking for people who would be successful, and so they deemed me as being a future success, which put me on good terms with the PR department. They could open doors for me. Like, I wanted to go meet Katherine Hepburn, and they got me tickets and stuff like that. Eventually I was able to meet Katherine Hepburn.

Breslin: That's wonderful. Was that fun? Interesting?

Luebking: They couldn't pull that piece of it off, because I wanted to meet her, but they could only get me tickets, so I sent a note back, saying that I was wondering if I could meet her and, if not, could I have her autograph and I was in a wheelchair. And then during the intermission, someone came up to me and said, "Miss Hepburn doesn't give autographs, but she'd be willing to give you a private audience after the show," so I went in there. It's actually when I learned the power of PR, because the *Chicago Tribune* had been with me up until the beginning of the show. The guy was so upset by my disability was all he could write about was how disabled I was going to be in that particular article, and then Knox read the article and also said that I shouldn't come back.

Breslin: Uh!

Luebking: And so we had to a lot of—

Breslin: Reverse public relations.

Luebking: Yes.

Breslin: Spin control.

Luebking: Absolutely. But ever since, I'm very leery of doing a lot of articles and stuff, not knowing the spin it would take. But it was interesting—Katherine Hepburn wasn't as tall as I thought she was. Covered with freckles.

Breslin: Is that right?

Luebking: Yes, she was just covered with freckles. It was interesting. Her assistant, I guess, came up next to her and held a program and pen and said, "Would you mind?" So I ended up with one of the few autographs of Katherine Hepburn out there.

Breslin: Is that right?

Luebking: Yes.

Breslin: She doesn't usually—didn't usually do autographs?

Luebking: Oh, no. It's only in her later years—it was after her injury in Connecticut, in a car accident that it was just a turnaround, and she started doing autographs. She would never do autographs, never do interviews.

Breslin: Do you still have it?

Luebking: Yes, someplace in my books.

Appreciation of the quality of rehab

Breslin: Okay. Anything else that you want to say about this period?

Luebking: I think when I was at rehab, I didn't know the quality of rehab I was getting because most of it seemed pretty logical to me. It was in a warehouse. We were in the old warehouse—converted warehouse—before we went to the new building. And so I had nothing really to compare the experience to. But over the years, I have met people who realized they didn't have the same quality of rehab that I had there. I think I learned more to appreciate what I did have.

Breslin: That's not an insight you can have when you're in the middle of it, with no points of comparison. It comes at a later time.

Luebking: Right. No, I mean, I had been told stuff like that, but, again, till you have a basis of comparison—but there were a lot of overwhelming stories on the floor. I was struck by that, and how people's lives were really devastated in so many ways. You know, in ways, I was very fortunate. I think part of it was just the identity I had was not influenced as much, like I mentioned before. I think also not being married, not having any dependents, being pretty young and therefore still able to adjust, various innate skills and various experiences all kind of came together in ways.

[Pause] I can't think of anything else right now.

Breslin: Okay. That's great.

Sharon Bonney

Research Interviewer/Editor Regional Oral History Office Disability Movement History

Sharon Bonney received a B.S. in Communication and Journalism from the University of Illinois and an M.A. in Public Affairs from the University of Iowa. After working as a reporter and freelance writer, she Established the Services for handicapped Students Office at Iowa before working in the Department of Rehabilitation as a client advocate in Tennessee.

In 1979, Ms. Bonney became director of the Physically Disabled Students' Program at UC Berkeley for nine years. She later was the assistant director for the World Institute on Disability. Since 1996, she has been an interviewer/editor for the Regional Oral History Office at UC Berkeley for the Disability Rights and Independent Living Project.

Her professional activities include numerous publications on disability issues; founding member, president, treasurer, and conference chair of the Association on Handicapped Student Service Programs in Post Secondary Education (now known as AHEAD); participant in the White House Conference on Handicapped

Individuals; and current member of the Society for Disability Studies.

Ms. Bonney has muscular dystrophy and is a wheelchair user.

Mary Lou Breslin

Research Interviewer/Editor Regional Oral History Office Disability Movement History

Mary Lou Breslin has been a disability rights law and policy advocate for over twenty-five years. In 1979 she co-founded the Disability Rights Education and Defense Fund (DREDF), the preeminent national disability rights law and policy center, and has served variously as DREDF's deputy and executive director, and president and chair of the board of directors. She is presently a senior policy advisor with DREDF directing the organization's research, and international law and policy initiatives.

During her career she has served as a policy consultant, trainer and lecturer on diverse disability and related civil rights topics. Ms. Breslin has taught graduate courses at the University of San Francisco, McLaren School of Business, and an undergraduate research seminar at the University of California at Berkeley. She also serves as interviewer and researcher with the Disability Rights and Independent Living Project of the Regional Oral History Office of the Bancroft Library, UC Berkeley. In 2000, she directed *From Principles to Practice*, the first-of-its-kind international disability rights law and policy symposium attended by attorneys and policy advocates from fifty-eight countries.

In 2002 Ms. Breslin received the prestigious Henry B. Betts award for improving the lives of people with disabilities. She also received the Paul A. Hearne Award from the Physical and Mental Disability Rights Committee of the American Bar Association in 2000, and a Mary E. Switzer Merit Fellowship in 1995. Ms. Breslin had polio as a teenager and uses a wheelchair.