Oral History Center
The Bancroft Library
University of California, Berkeley

Disability Rights and Independent Living Movement Oral History Project

Judith Heumann

Pioneering Disability Rights Advocate and Leader in Disabled in Action, New York; Center for Independent Living, Berkeley; World Institute on Disability; and the US Department of Education, 1960s-2000

Interviews conducted by
Susan Brown, David Landes, and Jonathan Young
in 1998-2001

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

Copyright © 2004 by The Regents of the University of California

---

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 Judith Heumann, dated January 2, 1998. 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.

Citation

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

> Judith Heumann, “Pioneering Disability Rights Advocate and Leader in Disabled in Action, New York: Center for Independent Living, Berkeley; World Institute on Disability; and the US Department of Education 1960s-2000,” an oral history conducted by Susan Brown, David Landes, Jonathan Young in 1998-2001, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2004.

Tape Guide

Interview 1: January 2, 1998
    Tape 1, Side A 1
    Tape 1, Side B 9
Interview 2: March 3, 1998
    Tape 2, Side A 19
    Tape 2, Side B 27
Interview 3: May 4, 1998
    Tape 3, Side A 31
    Tape 3, Side B 39
    Tape 4, Side A 48
Interview 4: May 8, 1998
    Tape 4, Side B 51
    Tape 5, Side A 61
    Tape 5, Side B 74
Interview 5: July 21, 1998
    Tape 6, Side A 81
    Tape 6, Side B 90
    Tape 7, Side A 100
    Tape 7, Side B not recorded
Interview 6: October 28, 1998
    Tape 8-1, Side A 103
    Tape 8-1, Side B 110
    Tape 8-2, Side A 114
    Tape 8-2, Side B not recorded
Interview 7: November 11, 1998
    Tape 9, Side A 119
    Tape 9, Side B 127
    Tape 10, Side A 134
    Tape 10, Side B not recorded
Interview 8: January 30, 1999
    Tape 11, Side A 145

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

Interview History—Judith E. Heumann

Judy (Judith E.) Heumann has been a prominent figure in the history and evolution of the disability rights and independent living movement, nationally and worldwide, for more than thirty years. Her vision of equal rights and access for all people with disabilities was shaped in early childhood by her experiences of discrimination after the onset of polio. Throughout her elementary and high school education, before disability rights even existed as a concept, Ms. Heumann questioned the practice of segregation-based special education. In 1970, after being denied a teaching credential by the New York City's Board of Education, Ms. Heumann's successful fight for the right to teach in public school led to the grassroots mobilization of disability activism in New York and the founding of Disabled In Action [DIA].

Later in the decade, Ms. Heumann moved to Berkeley to become deputy director of the Center for Independent Living [CIL]. In 1983, she cofounded and codirected the World Institute on Disability [WID] with Ed [Edward V.] Roberts and Joan Leon. Ms. Heumann received an appointment to the post of assistant secretary of education for the Office of Special Education and Rehabilitative Services during the Clinton White House years. Since 2003, she's held the position of advisor on disability and development for the World Bank.

Due to geographical logistics, staffing changes, and scheduling challenges—not only because of the narrator's long work hours and frequent travel, but also her notoriety as a telephone fanatic (addressed in her transcript as a compensation for lack of mobility)—Ms. Heumann was interviewed for the Disability Rights and Independent Living Movement [DRILM] project by three interviewers: Jonathan Young and Susan Brown, who lived in the Washington, D.C., area, and David Landes, a resident of the Bay Area. Mr. Young, at the time a PhD candidate in American history and a scholar of the disability rights movement, was not personally acquainted with Ms. Heumann but did extensive research in preparation for the interview by conducting phone interviews with Ms. Heumann's mother and numerous long-time friends and colleagues. He completed five interview sessions with Ms. Heumann from January through May 1998 before he was appointed to the Clinton administration as associate director for disability outreach, White House Office of Public Liaison.

After a several-month interim, the interview sessions resumed with Ms. Brown, formally Ms. Heumann's personal service assistant in Berkeley and later an employee of WID working in the area of disability policy. Ms. Brown conducted ten interview sessions, from October 1998 through May 1999, and left the project when she was accepted as a Peace Corps volunteer. David Landes, a member of the DRILM project team completed this volume of Ms. Heumann's interview, conducting two interviews in 1999 and 2001. Mr. Landes' acquaintance with Ms. Heumann dates back to the mid-1970s when they both worked at CIL in Berkeley.

The first and second segments of the interview, conducted by Mr. Young and Ms. Brown, took place in the dining room of Ms. Heumann's three-bedroom apartment in the prestigious Kennedy-Warren building located next to the National Zoo in Washington D.C. Ms. Heumann has resided there since 1993 with her husband, Jorge Pineda, and two personal service assistants. The common rooms of the apartment, as well as the couple's bedroom, are decorated with a blend of artwork and family heirlooms from Jewish/ American and Mexican cultures, the result of couple's marriage of more than ten years, and a collection of mementos from countries Ms. Heumann has visited to promote her work for disability rights. Myriads of photographs of friends and family pepper walls, dressers, and desks throughout their living space.

The third segment of Ms. Heumann's oral history with Mr. Landes occurred during two of Ms. Heumann's visits to the Bay Area, which coincided with one of many work-related trips for the U.S. Department of Education. One session was held at Ms. Heumann's hotel and the second at the Computer Technologies Program—a project which had originated at CIL during Ms. Heumann's tenure as deputy director.

Considered to be one of the most dynamic leaders and originators of the disability rights movement, Ms. Heumann's 400-page oral history includes her recollections of her personal development in relation to political and social awareness, which in turn birthed her own disability rights activism. Ms. Heumann also discusses her experiences with special education and rehabilitation services, first as a recipient from elementary school through graduate school, and later as the country's top administrator of those services. Other interview highlights include Ms. Heumann's accounts of working at CIL during its most groundbreaking period, her broadening awareness of disability issues brought on by foreign travel, and her numerous experiences of confronting discriminatory practices, from fighting the New York City Board of Education to leading protest demonstrations for access to public buildings, transportation, and civil rights.

Because of time constraints and logistical difficulties, Ms. Heumann's work after she left the Center for Independent Living is less fully discussed; in the future, we hope to add a second volume to Ms. Heumann's oral history to explore in greater detail her activities as cofounder and codirector of WID, as assistant secretary of education, and in her present position at the World Bank.

Ms. Heumann's transcript was lightly edited by Sharon Bonney of the DRILM project and reviewed by Denise Sherer Jacobson, also of the project. Because of Ms. Heumann's disinclination to read through the 400-page oral history, Ms. Sherer Jacobson—a longtime friend of Ms. Heumann's—noted parts of the transcript that needed clarification or further inquiry to jog the narrator's memory. (Throughout interview, Ms. Heumann often responded by telling the interviewer to call 'so-and-so,' if she couldn't remember details.) During a visit to Washington D.C., Ms. Sherer Jacobson spent four days with Ms. Heumann to complete the review of the transcript.

Denise Sherer Jacobson
Interviewer/Editor
March 16, 2004
Oakland, California

I. Family Background and Early Childhood

Family background

[Interview 1: January 2, 1998] [Tape 1, Side A]
[1]

Young: Judy, thanks for taking the time to sit down and begin our series of interviews. For this first interview, I'd like to go through some basic factual information, so I have a bit of an outline here. I'll let you take the lead.

Heumann: Okay. My full name is Judith Ellen Heumann, H-e-u-m-a-n-n. My date of birth is 12/18/47, and I was born in Philadelphia, Pennsylvania. My grandparents were all killed in concentration camps.

Young: Do you know when they were born, roughly?

Heumann: Actually, what you could do is call my uncle, Leon. I'll give you his number when we're finished. He could talk to you about his grandparents, and my mother can talk to you about her grandparents. I don't know when they were born. They're all from Germany, and we're all Jewish. My grandparents. I know they were butchers and let's see. I think my father's parents did their slaughtering, I think, behind the house, and then sold their meat from the house or from a store. I'm not really sure, actually.

My mother was an only child. My father—there were six children; two died before one year of age. There is my Uncle Leon, who's alive; Werner, my father, Alfred, Karl, and Leopold.

Young: That was your—

Heumann: Father's side of the family.

---

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

Young: Your father's mother had two kids that died.

— 2 —

Heumann: I think so. I think a boy and a girl. My uncle would love it if you interviewed him, actually. That would be great.

Let's see. My father I think was born December 7, 1919, and my mother September 29, 1922.

Young: How about your spouse?

Heumann: My mother and father were born in Germany. But, again, I don't know what town. I assume my father was born in Uffenheim, and I don't know where my mother was born. Jorge [Judy's husband] was born August 11, 1955, in Mexico City. My brother Joseph, September 27th, 1949; and my brother Rickie—hmm. He was born June 11th, 1954.

Young: I think she told me a year's difference, so I can put it together.

Heumann: Right. He's six years younger than me. Rickie is six years younger than me, and Joey is a year and a half. So Joey was definitely born in '49, and Rickie, I think—yes. He's forty-six now. He was born—you'll have to ask my mother. [chuckling] No one's ever asked me my brother's date, the year he was born.

Young: Where did you say you were born? In Philadelphia?

Heumann: Yes.

Young: Go ahead and review for me—

Heumann: Where I've lived?

Young: Speak about those places where you've lived.

Cities of residence

Heumann: Well, my parents moved to Brooklyn [New York] when I was about three months old. We lived in the same house my entire life in Brooklyn. Well, I don't know if that's exactly right. My parents lived at 657 East 38th Street until my dad died.

Young: What year was that?

Heumann: My dad died in March, 1991, but my mother didn't move right away. She didn't move for a couple of years. She moved, I think, in 1993 or 1994, then she moved to Ocean Parkway.

Young: Your parents lived in that house for—

Heumann: Forty-five years or something, yes. Now, when I went to college I lived in the dorms. I went to Long Island University in Brooklyn, so I lived in the dorms for the four years that I went to school.

— 3 —

Young: When did you start school? I know you graduated in—

Heumann: 1969. I started in 1965. Then in 1969 I moved across the street from the dorms to 190 Willoughby Street, and I lived there until I went to Berkeley, which I think was in, like, August of 1993.

Young: 1973.

Heumann: I'm sorry, 1973, exactly. Then I lived on Haste Street in Berkeley until 1974.

Young: But that wasn't all you were doing—

Heumann: I'm sorry. I was getting my master's degree at Berkeley.

Young: In public health?

Heumann: Yes.

Young: That was a one- or a two-year degree?

Heumann: It was a two-year degree, but I did it differently. We can talk about that later, but it was a two-year degree. I was supposed to do a six-month residency and then come back to school, but I didn't do a six-month residency. I did a longer residency, and they let me because I had had sufficient number of credits. What was going on at Berkeley, at that time, was if you didn't have a science background, they wanted you to take two years, and I had to do a six-month placement.

Young: Two years. Was that all course work? Or a year and a half of course work and then a six-month residency?

Heumann: Exactly. But they waived the additional six-month course work because I was back here in Washington, working for the Senate.

Young: The Senate was your residency?

Heumann: Right. I had enough credits for the one-year degree, and so they basically said that if I could pass the comprehensives, I could do a residency for a year, which is what I did.

Young: You were only there for one academic year.

Heumann: I was there for one academic year.

Young: And then came back here—

Heumann: Then I came back to Washington for my residency.

Young: For one year.

Heumann: A year and a half, actually.

Young: And then went back to Berkeley.

Heumann: And then I went back to Berkeley, right.

Young: So you would have gone back to Berkeley at the end of 1975?

Heumann: I went back to Berkeley, December 1975. I guess Lisa Walker is somebody that maybe you should talk to.

Young: Who was she?

Heumann: She was the person I worked with when I was working in the Senate.

Early life in Brooklyn

Young: Tell me a little bit about your home in Brooklyn.

Heumann: Like about the house or the neighborhood?

Young: Yes. What was the town like?

Heumann: The town [laughing].

Young: Neighborhood.

Heumann: Brooklyn a town, hmm. Four million people in this town [chuckling]. We moved into the neighborhood, and I think a lot of the families were moving in around that time, after the war. The block that we lived on was mainly private homes, detached and semi-detached. It was a primarily Christian neighborhood. We were very close with a lot of the families on the block, and I'm still friends with a number of the people I grew up with. It was a pretty, you know, working-class, lower middle-income neighborhood. It was a close neighborhood. We called some of the neighbors aunts and uncles.

Women were mainly housewives. The women were all housewives. Really none of the women worked outside their homes; they all did their work in their homes. There was a guy who was a poet and a man who was a police officer and a person who was a high school teacher and a firefighter, and my father was a butcher.

It was a very friendly neighborhood. We used to do a lot of things together.

Young: Games?

Heumann: Yes, kids played together a lot and were in each other's homes a lot.

Young: I haven't been to Brooklyn.

Heumann: I could tell when you called it a town [chuckling].

Young: That was a mistake. I didn't know that Brooklyn was a city. Did you stay there for the most part, or did you travel to other parts of New York a lot as a child? Were your surroundings primarily that neighborhood is what I'm asking?

Heumann: Well, I mean, we went to the theater in Manhattan. We would go to the ballet, and we would go to the opera, and we'd go to light opera and things like that. But mainly speaking, when you're a kid, except when you visit friends and family and do things like that, you're mainly in your neighborhood. So I spent a lot of my time in Brooklyn because most of my relatives lived in Brooklyn. Some of them lived in Queens, and some lived in Manhattan. I'd go to Long Island. But I didn't frequently travel outside of the New York surrounding area, like Philadelphia, New Jersey, New York and upstate New York. I didn't travel on an airplane until I was in college.

Young: Why did your parents move to Brooklyn?

Heumann: Because my father's family was mainly in Brooklyn, and my dad was going to open up a—I'm not sure he moved because he was opening up a store or wanted to open up a store. I don't know. I think that was basically—his brother lived in Philadelphia, but his brother died in 1947, before I was born, so I'm not exactly sure whether his brother dying had anything to do with him coming to Brooklyn. But my mother and uncle would be able to tell you that.

Young: I did get this from your mother, but we'll make sure we have it right by doing it a second time. Tell me the different schools you attended prior to college.

Heumann: It was home instruction and P.S. [Public School] 219, then Sheepshead Bay High School.

Young: What was the high school name again?

Heumann: Sheepshead Bay.

Young: What did you study in college?

Heumann: Speech and theater, with an emphasis in pathology. Two degrees: a BA and a master's in public health, MPH.

Assistant Secretary at Rehabilitation Services Administration

Young: Tell me about your current job.

Heumann: My current job. I'm an assistant secretary who has responsibility over the Office of Special Education and Rehabilitative Services. I have a staff of about 370, a budget of a little more than $7 billion, and I have responsibility over special education, rehabilitation, and the National Institute on Disability and Rehabilitation Research [NIDRR]. All three components have a political appointee over them who reports to me.

Young: Kate Seelman is with NIDRR. Who are the other two?

Heumann: Fred Schroeder, who is the commissioner of the Rehabilitation Services Administration, and Tom Hehir, H-e-h-i-r, who is the director of the Office of Special Education programs. I have responsibility over those programs: working on budgets and legislation, development of legislation, working with Congress, the development of regulations; once legislation is passed, implementation and appropriations issues; and then working within the department on the overall education agenda of the department and helping to assure that disability is integrated throughout the department's agenda.

Young: Is that something that you wanted to do for a long time, to be in a big government position, or is that somewhat serendipitous?

Heumann: Probably a little of both. I had worked for a short period of time with Ed Roberts in Sacramento in the state Department of Rehabilitation and had decided at that time that if I ever would work for government, it would have to be a position which had a broad reach of responsibility. So after the campaign, when the President [Clinton] was elected, I was asked if there were any positions I would be interested in, that was the one that seemed a more natural position because it was over, you know, major areas.

Working with political appointees

Young: What are your daily responsibilities like? If you have three political appointees for each of the three divisions, how do you spend your days?

Heumann: I try to be as knowledgeable as possible about the work going on in all three components. My work really varies, depending on what's going on. So when we were working on the development of the IDEA [Individuals with Disabilities Education Act] statute, I spent large amounts of time working with the director and his staff on policy issues around the legislation. And it depended. Sometimes I would meet with staff who had done work and were reporting in on what their recommendations were. Sometimes I would meet with them to help design what I wanted them to be thinking about.

With the IDEA reauthorization, I spent a lot of time, a lot of time on policy issues, a lot of time working with the House and Senate staff people, a lot of time working with constituency groups. I guess more time on the development of the IDEA reauthorization because it was such a huge task. Now I've been spending a lot of time on regulations. Again, there's a core group of staff that do the bulk of the work and work with me on policy issues, when there are disagreements, or when decisions have to be made about what direction to go in.

I work on budget issues, I work on setting priorities for discretionary grant programs. Basically this job is kind of a unique job because there are three political appointees. If I were to do it, I'm not exactly sure how I think about this, as to whether or not it's the best thing to have three political appointees or not.

Young: There's a lot of changeover every administration?

Heumann: Yes. I mean, they're deputies, and the deputies don't change, but the nature of government is such that when you're the director of a program and you're a political appointee, your goal is not necessarily to work on a team. You know, most people come to D.C. to advance themselves; some people come to D.C. to advance an agenda; some people come to D.C. to do both. But this job, I think, is mired in the fact that I came to this job with the goal of having people work together, all three of the components working together. Historically, that never had happened.

Young: So having four political appointees makes things work somewhat at odds.

Heumann: There's actually more than that because I have a political deputy, and then we have one, two, three, four, five lower-level political appointees. But I just think that if the place had run in a more collaborative way before I came there, it wouldn't have been as difficult as it can be sometimes because that environment would already exist, but that environment hasn't existed, so it's creating it. I think, you know, it's got its bumps. But it moves slowly forward. The question will be when I leave, how things continue to move forward.

Young: I understand you like to sleep in in the mornings and show up to work around ten, eleven o'clock?

Heumann: Yeah, right [laughter]. I get up about—well, it depends. I get up at a quarter to six. Sometimes I get up earlier. Sometimes I start working in bed around four; it depends. I get home somewhere between seven and eight or later.

Young: You're in the office for a good twelve hours.

Heumann: I get to the office about eight-thirty and so I leave the office—depending on the time of year, I leave the office different times, and depending on what's going on. But I really never leave before six-thirty or seven. So I'm usually in the office, you know, ten to eleven hours a day. But then I started working before, and I'd come home and sometimes I have a meeting; sometimes I have dinner with my husband, and then I do more work. So I usually go to bed between eleven and twelve. I'm on the phone a lot [chuckling].

Young: People tell me about your one, two, three, four o'clock in the morning phone calls.

Heumann: [chuckling] Well, see, now it's different. When I lived in California, what I used to do more was to get up in the morning and then be able to call back East, so now it's a little bit more difficult with the time change. So it's more likely that I'm making the calls at twelve or one in the morning to them back in the West Coast. Yes, I'm up a lot.

Social interests

Young: I get the impression from a number of sources that your work and your vision and your commitment to people with disabilities are a huge part of your life. Time, emotional commitment, energy. Tell me about some of the things that interest you besides your work in the government and your business calls. What else do you like to do?

Heumann: I wouldn't define my work as work in the government because this is only a temporary job, so I've always worked like this. What else do I do? Well, I try to go to the movies. I like to go to the theater. I like ballet, but I haven't been in years. I like the opera, but I haven't been in years. I like to go to museums. Things happen in spurts. My brother was here this summer, so I did a bunch of museums. I guess since December we've gone to the MCI [D.C. cultural place, MCI Center, which is a center for basketball, concerts, etc.]. Did it twice. I like ice skating. There are few things that I will drop my work for, but if ice skating is on, I'll try and watch ice skating on TV.

I like spending time with my friends, talking to my family. I like spending time with some of the older relatives and trying to find out about the history of the family, my family.

Young: Has anybody tried to do a genealogy?

Heumann: I don't think so, really.

Young: Do you still sing?

Heumann: Yes, but I don't study any more. I haven't studied since I was twenty-five, so I don't do anything professionally or amateur. I just kind of sing at the synagogue and in the house. I think about it, but I don't have the time right now.

Young: Neil [Jacobson] tells me the synagogue has been an important part of your life.

Heumann: Yes. You know, more so in California than here. Here in D.C. the synagogue in the neighborhood is a very big place, and I really don't know a lot of the people, and it's not what I'm used to. I'm used to smaller synagogues. But the synagogue in California [Congregation] Netivat Shalom—whenever I go back on business, I always go to shul. I'm a member out there. Yes, my religion is a big part of my life.

Young: We'll come back to that. We're going to take you back in time again momentarily. Anything else you'd like to add about what you do currently?

Heumann: I assume we'll talk about more of this later, right?

Young: Yes, we'll do that.

Heumann: I think a big part of what I do now, actually, is try to work on getting a bigger agenda, not just in the area of education but working with people in other agencies to look at the entire picture of what disabled people need and what we get and what we're not getting, and trying to help advance a broader agenda. It's happening somewhat. I think there's a real advantage of understanding government. When you're working in a job like I am, you have only so much time to do other things because I spend so much time, you know, in this job specifically.

It's really been, I think, one of the dilemmas for me of when do I delegate, when don't I delegate. I think part of it probably, really, is a trust factor. When you come to this kind of a job, everybody that I brought in were people that I'd never worked with before. So while this administration was really very good, in our department at least, in letting the assistant secretaries interview and make our recommendations to the secretary, all of which he honored, I still, nonetheless, didn't know them. I knew Fred a little bit, but a little teeny bit from California, I had met Kate a couple of times, and I had met Howard Moses, who's my deputy. Howard is somebody you might want to talk to, actually.

But I hadn't worked with them before, and so, you know, you come into these jobs not knowing how the jobs run and everybody is coming in together, not knowing what you're doing. You start running; you don't start slowly [chuckling]. You get dropped down, and it's full speed ahead.

I don't remember what your question was.

Young: I want to stop the tape.

Early childhood and family relationships

[Tape 1, Side B]

Young: Judy, how would you describe yourself as a little girl? What were you like as a child?

Heumann: I never really thought about that. Probably inquisitive. I think I liked to play. I liked my friends. I liked to play dolls. I loved dolls.

Young: What kind of dolls?

Heumann: Ginny dolls. I think we had ballet dolls.

Young: No Barbies?

Heumann: No, Barbie wasn't out yet. Ginny dolls were in then. We used to do that a lot. I liked the phone pretty early on because it was a way for me to talk to people when I couldn't get to their places. I was a happy kid.

[added by Ms. Heumann during the editorial process: I would sit on the steps of my house, or a friend's house, and we would play with the dolls using a different voice and doing children's make-believe talk. I loved to put the shoes on my fingers—the third and fourth fingers—and walk with them. I learned to dance this way. I still walk and dance with my fingers—always my left hand. Arlene Mayerson's daughter Emma and Diane Lipton's daughter Daria recently gave me shoes for my fingers so I could dance.]

Young: How did you and your brothers get along?

Heumann: I think like brothers and sisters get along. We got along basically well. We had our fights. When my parents bought the house, I didn't have my disability, so they bought a house that had two floors. So when I had polio they then built an extension onto the first floor. My brothers slept upstairs, but I slept downstairs. I didn't start sleeping downstairs until I was about eight or nine years old. I think before that my father would carry me up and my mother would carry me down, but as I was getting bigger it was too much for my mom to carry me down, so that's when I moved downstairs. So I think from that perspective our relationship was somewhat different because if I didn't have a disability, my brothers would have shared a room upstairs and I would have been upstairs. So we didn't have that level of interaction.

I had a lot of friends. I used to go to my friends' houses a lot. I participated in everything that we did in the neighborhood. I was in Brownies. I went to Hebrew school. Took piano lessons. Later I was in Girl Scouts. I liked dancing; always liked dancing. I used to be in plays, at the synagogue first and then in elementary school, only with disabled children, then when I went to camp. Camp was a very big part of my life. I guess I started going when I was about nine. First, I went to a place called Camp Oakhurst.

Young: How do you spell that?

Heumann: O-a-k-h-u-r-s-t, in New Jersey. Then I went to a camp called Camp Jened, J-e-n-e-d, in Hunter, New York.

Young: I want to come back to those. Tell me about your parents.

Father and mother

Heumann: My parents were loving parents. They were very driven. Driven. They worked very hard. My father and my uncle opened the store, L&W Heumann Meats, Inc., in the fifties, and they worked six days a week. My dad used to leave the house at, like, three-thirty in the morning and got home at probably seven-thirty, eight, eight-thirty at night. My mom worked half-time for my father, and my aunt worked half-time.

Young: Do you remember seeing your father much?

Heumann: Oh, sure. When he came home every day. I saw him every day. That may be one of the reasons why I started getting up early in the morning because—

Young: Stayed up late and got up early.

Heumann: That's right. He was up late. He read a lot. He wouldn't sleep through the night. We always laughed at my dad because he would fall asleep [chuckling] obviously because he didn't get a lot of it, so he'd fall asleep at the table after he had eaten or he'd fall asleep reading. He read a lot when he was home, and he and my mom were family people inasmuch as—we did a lot with his relatives and my mother's relatives. Well, my mother didn't have as many of them as my father. There was, like, a family circle, so we used to get together with people, like, once a month. But we used to see my relatives, like, on Sundays. Visit my uncle Alfred or my uncle Leon or my cousins on 7th Street or different places.

My father was into theater, museums. I think it's amazing all the things we did, given the number of hours my father worked, because on Sunday we would get up and I would go to Hebrew school; my brothers would go to Hebrew school; and then when we came back we would frequently go to the theater, go to a museum, go do something. We ate together on Sunday; tried to eat together Friday night or Saturday night.

Young: Your dad didn't eat with you, then, during the week.

Heumann: No, because we'd eat earlier—by the time he came home—but my mother would eat with him. My mother took care of everything else, you know? She took care of us, and she chauffeured us around during the day. She made sure we were doing our homework. My father was very involved in that stuff, too. My father didn't graduate high school, and my mother went to a little bit of college. But school was something that was very important for all of us. We had to go to school.

Young: Why didn't your mom finish college?

Heumann: I assume because she met my dad. Got married. She never went to school full-time. I mean, they were both trying to raise money to try to get their parents out of Germany. Well, my dad went into the war, and my mom worked for the War Department, I guess. I'm not sure if she was in school—I don't know when she was taking some college classes—and I don't know how much college she did, but she wasn't a full-time student.

Young: When did your dad go into the war?

Heumann: Pretty early. You have to ask my mother the dates.

Young: Okay. What did they tell you about your grandparents?

Knowledge of grandparents and anti-Semitism

Heumann: That was kind of interesting because of the way my grandparents died. You learned things kind of along the way, but because we didn't know them—my mom didn't know my dad's parents; my dad didn't know my mom's parents—there were no shared experiences. So I don't really recall a lot of—there were pictures around. We knew they had been killed, and my parents would talk about them from time to time.

We didn't buy anything German-made. We didn't buy anything Japanese-made. My father and my uncle, in particular, had very, well, my mother too, of course, strong feelings. They didn't teach us German. They didn't want us to learn German. It was very apparent. They would talk German amongst themselves if they didn't want us to understand something. They didn't talk a lot. We would have to raise the discussion, ask things.

Young: Did you know how they died in the beginning?

Heumann: Yes.

Young: When would you have found that out? How old would you have been?

Heumann: As early as I would have remembered it. There was nothing that was ever held back about that.

Young: How did that strike you? I would think that would be devastating.

Heumann: But, you know, you have to really realize this in the context of being Jewish and just the whole issue of anti-Semitism historically. I mean, I think it was something that, as I got older, I thought more about because they were never there, so it wasn't like I had them and then I lost them.

Young: No real sense of loss in the sense of missing something—.

Heumann: Well, there's a sense of loss inasmuch as if friends of mine had grandparents, and usually people didn't have four grandparents, you know, so if people would talk about their grandparents, then it would feel, then I would realize differently, you know, that I didn't have them and I never had them. It's the kind of subject where, you know, you have to be of a certain age and intellect, I think, to be able to start really comprehending what all of this really meant. We studied about it. It was certainly nothing that was ever hidden in my family about it. And remembered stories which still today I don't know all the answers to.

Thoughts on being Jewish

Young: You mentioned a moment ago that you had to view it in the context of anti-Semitism. What types of racism did you sense as a child?

Heumann: Racism?

Young: Right. A lot of hostility toward you and your family? You said it was a predominantly Christian neighborhood.

Heumann: No. No, I really didn't at all. We were different. You know, Christmas time we didn't have a Christmas tree and we didn't have a wreath and we didn't do any of that, but we went into our neighbors' houses, and we got Christmas presents from them. The biggest difference was how, as Christians, they were raised to believe that you had to be baptized and if you weren't baptized you couldn't go to heaven. I remember worrying about that. On Sunday nights, when I listened to the radio while I was going to sleep, there were no music programs at the time because all they had was religious programming. So they had these heavy Christian programs about Christ. At that time, there was, I didn't feel this from my neighbors, but you knew it was going on, this belief that Christ had been killed by the Jews. Christ wasn't anything to us. I mean, I learned about this figure, Christ.

My parents were very respectful of other people's religions, which I think was also very important. I found that the people that we lived with were very respectful of us. I don't ever remember anybody pushing us, pushing me to be anything but myself. We didn't dwell on it a lot. A bunch of my friends went to Catholic schools. But my mother was very active in the neighborhood always. My brothers were in Little League. I think it was

sponsored by the Catholic Church, so they were friends with the priests, and it just kind of was.

Young: How are you a different person because of your grandparents' having been killed in the Holocaust?

Heumann: I think it's broader than that. I don't know if I'm a different person, but how am I as a person whose family grew up in Germany and then left or didn't leave because of that? I mean, I hope it's made me more sensitive to discrimination. Over the course of the years I've been to Germany a number of times. What strikes me about what happened there is very much how there was so much denial and still is so much denial about what actually happened. I think that, to me, is something that on some level I think about a lot, which is how can you be in a situation where you can deny things that are going on to such strong degrees?

Which in a very real way happens here in the United States. Well, the magnitude of the problem is clearly different because, you know, in Germany you had concentration camps a few miles away from major urban areas, with people denying that they knew anything was going on, although people were disappearing from their neighborhoods, never to be seen again. This belching smoke was coming out in the stories. So that incongruity, if there's such a word—.

But here I think it's also whether or not you want to pay attention to what's going on in communities that middle-class and above people don't live in and can avoid and can just deny the existence of poverty in the United States.

Young: So that's a really powerful metaphor of the whole idea of being aware.

Different responsibilities as a Jewish person

Heumann: I think for me, being Jewish, has always meant that I have a different responsibility.

Young: A different responsibility to yourself or other people?

Heumann: Other people.

Young: And what is that responsibility?

Heumann: I just think it's needing to take responsibility for more than myself and needing to take responsibility for what does go on in my environment and not just cavalierly saying it's somebody else's responsibility other than my own.

Young: Why wouldn't it be the opposite? If you have ancestors who were brutally murdered, why not have a sense of "I'm just going to look out for me because other people weren't looking out for my family, so I'm going to make sure that I look out for me"?

Heumann: Well, because I've never felt that looking after oneself—I mean, I'm always looking out for myself. I think you just always do look after yourself. But I've never felt that just looking out for yourself can fix a problem. If it's a large problem, it's not one that affects just one person, and so I've always felt that it's better to work with more people rather than with fewer people.

Young: Anything else you'd like to add about your grandparents?

Heumann: We can talk about it another time. I'll think about it.

Young: Okay.

More on mother

Heumann: About my mother. I think my mother, when we were growing up, she had a lot of responsibility because she was raising three kids, and there was so much problem with my getting into school. She really had to start doing work to get me in school. They were never prepared for any of this. I think for both my parents, on a certain level, it was probably, you know, a rude awakening to what they probably thought would happen here. You know, it's, like, my mom takes me to school and I don't get to go to school, and I don't get to go to school because I'm in a wheelchair. So that wasn't in their plan.

Young: You mean they had thoughts that America was a better place than that?

Heumann: I don't know if they would ever say America wasn't a good place or a better place. I don't think they'd use those words. But I think probably that they were surprised. Did you talk to my mother at all about this?

Young: [no audible reply, but obviously affirmative]

Heumann: What did she say? I never talked to her about it, really.

Young: What did she say about the problems of you getting into school?

Heumann: Yes. Did she talk at all about what—

Young: I want to keep my voice at a minimum on the tape, but I think for her she never thought differently of you for having a disability in the sense that that didn't entitle you to anything less than anybody else.

Heumann: Right.

Young: So she talks about not having reflected on a lot of things relating to that process because she sounded very pragmatic. What good is reflection going to do? You've just got to do it.

Heumann: [chuckling] That's my mother.

— 15 —

Young: She didn't spend a lot of time thinking about what led up to this, why is this the case? It was more the fact of, I want my daughter to have a good education, and I'm going to do darn well whatever I can—

Heumann: Now.

Young: —to make sure she does.

Heumann: Now. Exactly.

Young: That's the sense that I got from her.

Heumann: Yes. I think, you know, that's exactly the way my mother was, and is. It's don't look back; always look forward. What's the problem, and what do we have to do to deal with it? So I think it's very funny when you think about all the things that she did, given her background, and how she [chuckling] certainly—she didn't come from a political family in Germany or the family that she lived with here in the States. I think they were just kind of—you know, they lived in their community. They did what they did in their community.

Young: It sounds like she has incredible perseverance.

Heumann: Right, she does. She learned as she went. I think what I learned from my mother and my father around this individual approach, my mother never just approached things for me. I mean, she did in the beginning because her first experience was me not getting to school, so the first thing she had to do was get me into a school. But once I started going to P.S. 219, she started working with other parents. When they found out that if kids were in wheelchairs they were going back onto home instruction, she worked with other parents to work with the Board of Education.

I mean, I very much believe there's strength in numbers, and I think my mother believes very much there's strength in numbers. There's also something about protection [chuckling] in numbers when you're not out there by yourself. It's a reassuring factor, I think, to have other people who share similar goals, to reassure you that what you're trying to do is a good thing to do, or at least the right thing to do, not necessarily the good thing, but the right thing.

Effects of polio on Ms. Heumann's life

Young: Judy, you obviously, having polio at the age of eighteen months, have never known not having a disability. How did that make a difference in your life in the earliest years, having a disability?

Heumann: I can't say how it made a difference because I didn't have one and then the other. For me, it just was a part of who I was. Obviously, I knew that I was different from the other kids. I didn't do things the way other kids did them. As I got older, that was a bigger issue in my life than when I was younger. Because when I was younger, I think I did know that I was doing things differently. By and large, I did them anyway. Or my family helped me do them, or my friends or their parents helped me do things. I don't remember thinking a lot that I was prevented from doing things that other kids did.

I mean, even in the neighborhood, when kids went roller skating, sometimes I would just watch them roller skate, but other times I put skates on and moved forward in my wheelchair, and my friends would push my chair, so I would play skating.

I didn't have an electric wheelchair, and I think that would have been a helpful thing. They didn't exist when I was younger, but then, when I was older, my father said when I could afford to buy one, I could buy one. But he didn't think they were necessarily good.

Financial support

Young: Tell me a little bit about the disability in terms of functional impact. I know you use a wheelchair now. Had that condition been pretty consistent over time? Was it more severe when you were first having polio?

Heumann: No. Well, yes and no, but I don't remember because I was so young. I was in an iron lung for a couple of months, and then, I think, my mom took me for treatment on a regular basis. I think I was in and out of the hospital for about a year. What did she say? How long was I in and out of the hospital? Do you remember?

Young: I don't remember.

Heumann: Yes. I think I was in and out of the hospital for about a year, and then I went for treatments, and then we had a therapist who came to the house, and then I went to Rusk Institute for three months. So, you know, I did things differently than my brother. I don't know, but my brother was born just at the time that I had polio, so I think there were issues there because my mother would be at the hospital a lot, and so he would be taken care of by other neighbors. The neighbors were very good because they helped my mom a lot.

I remember once in Brownies—or Girl Scouts; I can't remember—they went to an ice skating rink and they said my wheelchair couldn't go in the ice skating rink. That was the only time I ever remember not participating in an activity. [ringing telephone]

Young: Were you ever able to walk?

Heumann: I used to use crutches and braces, and I stood a lot, and I walked, but I never walked very well. I would walk in my house. I didn't use the wheelchair a lot in the house, although I did for my homework. But the doctors were always saying I needed to stand as much as possible. I stood in the car; I stood at the house. I used to walk, as I said, in the house, and then sometimes I would walk outside, but never very far, and I walked very slowly. So once I had my spinal fusion in 1968, I didn't use braces again after that.

Young: What was the purpose of the spinal fusion?

Heumann: To straighten my back so it would stop curving.

Young: And you weren't able to walk after that?

Heumann: No. I mean, my walking was with crutches and braces, and what happened after I had my spinal fusion was I had to get a new pair of braces. They went to order me a set of braces that weren't the right kind, and I told them that I didn't think they were ordering me the right kind of braces. They insisted that they were. So when I got them, they weren't, so I just never got another pair.

Young: Shall we stop for now?

Heumann: Sure.

II. More on Onset of Polio and Early Experiences

Onset of polio and early recovery

[Interview 2: March 3, 1998] [Tape 2, Side A]

Heumann: —because I was less than five years old. So a child at that age doesn't really have an analysis of what was going on.

Young: So did you only undergo any type of physical therapy or rehabilitation when you were five and younger, or go on at all later in life?

Heumann: I had therapy at home, I guess, for a few years when I was younger, and I had physical therapy when I was in school until I was eight years old—until I graduated from the eighth grade. But therapy was never an overpowering part of my life.

Young: So was it just sort of strengthening exercises, that type of therapy?

Heumann: Yes. I mean, you know, keeping my tendons not tight. I was different than a lot of other people. My parents weren't into surgery. I also wasn't in the hospital a lot. I mean, I was when I first had polio. When I first had polio, I was probably in the hospital—I'm not sure—maybe up to a year. I don't really know the answer to that. Like, most of the time. Then, when I came out, I think they took me for Sister Kenny treatments.

Young: What do you mean by Sister Kenny treatments?

Heumann: Sister Kenny was a program for polio, and they had a certain type of medical treatment or therapy treatment, but I don't really know what it was. I was just, like, three.

Young: Okay.

Heumann: So I don't remember it. When I was four, I think is when I went to the Rusk Institute, and that was for three months. My parents would pick me up on Fridays and bring me back on Monday morning. What I remember about that was I didn't like going, and my parents visited me on Wednesday afternoons. They [the Rusk Institute] wanted you to come back on Sunday nights, and my parents didn't feel that there was a reason for me to come back on Sunday night because they didn't do anything on Sunday night. So I kind of have this vague recollection of them saying that I should be coming back earlier and my parents not, but I don't really know how involved that was. But I remember those kinds of discussions.

We stopped going to Rusk Institute, even on an outpatient basis, when I was a little more than five years old, I think. One of the doctors had given some kind of a prognosis about what I would and wouldn't be able to do. My parents just thought they had no ability to make these kinds of prognoses at this age, so we stopped going there. I became a private patient of one of the doctors that we met at the rehab hospital.

We had an Israeli guy who came over to the house and did therapy once a week, and I want to say, like, I don't know—I really don't know for how long—but I think I was four or five when that started. My father used to do some therapy with me, stretching and things like that. Then when I was six I had tendon releases. I had surgery. I was in the hospital for about two weeks. What I remember most about it was that I was in the hospital for two weeks and certainly didn't like that, but then I was home.

I remember the day that they were supposed to pick me up, there was this big hurricane, and a nurse came and asked me if it would be okay if my parents picked me up the next day, and I said no, so someone came and picked me up that day.

I don't remember if it was Dr. [Meyer] who recommended that I have some kind of thumb surgery. It's one thing that polios could do is you transplant muscles. I can't use my right thumb; I can't cross my right thumb over to my pinkie, so someone had suggested that they do a muscle transplant. I remember my parents taking me to see another doctor, and the other doctor saying, "Well, if it were my child, I wouldn't do it." That was the end of that.

Curvature of the spine and surgery

Heumann: So then I had another surgery when I was in college, when I was a junior. I had a spinal cord injury. I had a spinal—

Young: Fusion.

Heumann: Fusion. But I made that decision myself.

Young: That, as I recall, was to prevent curvature of the spine?

Heumann: I already had curvature of the spine. It was to prevent further curvature of the spine and to help correct as much of it as possible. I had good bracing, and the bracing basically had prevented the curvature from getting as significant as it would have gotten if I didn't have good bracing. But I was having pain, and it was also getting to a point where you needed to have it within a certain age range, and I was on the upper end of the age range, so I just decided to do it.

— 21 —

Impact of medical professionals

Young: You speak about all of this very matter-of-factly.

Heumann: I've talked about this to people before, so—

Young: You've got it down.

Heumann: Yes, but, I mean, it didn't impinge on my life like I think it did on other friends of mine who were in rehab facilities for months and for years and were sent away from their families for long periods of time. So they didn't really know their family the same way. You know, other friends of mine—it seems like they allowed—their families allowed the medical profession to rule over the lives of the kids. There was also, I think, much more of a feeling that the surgeries that my friends went through were also to make them better. Whereas we had our own things. So I had the tendon releases and then the doctors would say, "Well, if you sit too much, you'll get the contractions again." I remember standing at meals and standing in the car and standing lots of places. It still is in the context of being within the family.

So I think the biggest thing that my parents bought into with the medical community was when the doctors said that I needed to walk, and there was this sense that walking—that I could continue to improve and get better—although I never had the sense from my parents that getting better meant being cured. But, you know, the Germanic approach of exercising and health was definitely part of that. So there was always making sure you didn't eat too much so that you didn't gain weight, because, if you gained weight, it would be too difficult for you to get around. My mother actually told me once that if there was one thing that she could do differently as a mom, it would be not to have worried so much about what we ate, weight stuff.

Controversy about power wheelchair

Heumann: But when I was twelve, I think somebody wanted to give us a free electric wheelchair, which in those days—that was pretty early because at twelve it would have been 1958 or 1959—(I'm just crossing my foot, so when you listen to this tape in the future, you know why all the clicking is going on, because I'm moving my wheelchair back and forth)—but my father wouldn't take the chair.

Young: Why?

Heumann: Because he didn't want me to become too dependent on it, because he felt that if I got it I wouldn't exercise. I think therein lied the problem of the therapies and the therapists. They didn't teach families that, you know, for some people therapy could result in really a greater degree of independence, autonomy, or the ability to walk more normally. In my case, that was never a realistic expectation because I had a certain level of strength that I had regained, and I was never going to get much more.

— 22 —

But he had said that when I was old enough to be able to buy one myself, I could have one, but that he wasn't going to get me one. It was really out of this sense that it wasn't a good thing for me to have.

Young: Did you agree with him?

Heumann: It didn't matter [laughing]. Did I agree with him!

Young: Did you really want that?

Heumann: No. You know, was I angry? I'm sure I was. In 1958 or '59 I didn't know people in motorized wheelchairs. There weren't many of them. So if I would have gotten one, I would have been the first on my block, the first [chuckling] in my neighborhood. The first in my town. If it would have been in 1969, it would have been very different because by 1969 already there were many people who were getting chairs. I think "Ironsides" had been on TV and all these different things.

So no, I remember thinking that I was going to get one and when I was, like, twenty or twenty-one, I bought my own. Now, that was very interesting, when I did get my first motorized wheelchair.

Young: Let's hold that for a moment, before we get to that. How are you getting around?

Heumann: I don't want to hold it. I just want to tell you something?

Young: Okay.

Heumann: Because I think it flows from it. I got around in a manual wheelchair, and I had to be pushed, and I could push myself a little bit. But I couldn't push myself up and down a block; I couldn't push myself across the street; and I was never able—I used crutches and braces—but I was never able to ambulate up and down steps at all. I couldn't go up and down steep hills. I had very bad balance; if I fell, I couldn't get up. I couldn't sit down by myself; I couldn't stand up by myself; I couldn't do any of those things.

But, you know, your family helped you. The professionals didn't help me or my family look at what normal transitions should have been and didn't help look at when exercising would have been a good thing because exercise is good for everyone and what type of exercising would have been okay for me or good for me. Like practicing my walking. That wasn't really discussed.

So what basically happened over all of these years was that I wasn't able to build up my strength to do the things that the doctors implied—I don't think they ever said it—but there was this implication. It was an implication not just of getting weak, but an implication of not getting stronger if you didn't do certain things.

Young: It sounds like they felt you should do these things, you should be getting better.

Heumann: No, I don't think it was a "should be getting better." I never felt a "should be getting better." But you needed to do these things so that you wouldn't lose your strength, and maybe if you did these things maybe you'd get stronger. But I was very young when I realized that the "if you got stronger" routine wasn't going to happen to me. I think for certain people, kids, it maybe did a little bit, for kids who had different types of disabilities.

Independence with power wheelchair

Heumann: But I think that what people didn't talk about then either was what are the normal stages that children go through in obtaining levels of independence? What do they do? If you're not able to do those things, what kind of an impact does it have? So, you know, whereas at the age of eight or nine people started leaving their block and starting going places more independently, whether it was to the stores or wherever. I wasn't able to do that, so I always had to have somebody with me because I couldn't literally get off the block and go across the street.

So when I was twenty-one years old and I first got a motorized wheelchair, it was the first time in my life that I was ever out on a street by myself. I don't remember when I first got the chair, but I remember one of the first incidences I had. An argument with my roommate. I left the apartment. I wasn't really angry enough to warrant leaving the apartment, but it was the first time in my life that I could leave the apartment, and I remember [chuckling] leaving the apartment.

I lived in a bad neighborhood in Brooklyn because I wasn't living at home anymore. It was down near Long Island University. Going outside and saying, "Okay, now that you're outside, you can't go right back in." So I went around the block. I remember going around the block, and it was such a liberating experience to be able to leave a place and not have to ask somebody to leave it with you, which of course you wouldn't do. If you're angry at somebody, you're not going to say, "I'm angry now. Would you please push me around the block?" You know, since I had never been down a street by myself, it took me years to learn to do that because I always had somebody to talk to.

Young: What did you have to learn?

Heumann: How to be by yourself.

Young: What was hard about being by yourself?

Heumann: I had never been by myself. I mean, when I went outside, I was never by myself for more than a couple of seconds. You know, I'd go outside my parents' house and roll two doors, and a friend would come out; we would play. But I never went for walks by myself. There never was anything I could do, you know.

Young: Did you think about that at all before you had the wheelchair, that you weren't getting out on your own? Or was it more once you got the chair, you looked back and you thought, "Boy, I've never been out on my own like this!"?

Young: I don't think those are inconsistent. I think it would have been possible for me to think, "What would it be like if I could do these things?" and a whole different experience to say, "Oh, I am doing these things." It's one thing to anticipate what might happen; it's another thing to actually be in the moment when it is happening, and they're very different experiences.

Delayed first-time experiences

Heumann: When I think about those kinds of feelings, it was like when I taught the second grade. I know we're not there yet, but when I taught [chuckling] the second grade, I realized the day the kids were coming into class that it was the first time in my entire life that I had ever been in a second-grade classroom. It was a very bizarre experience because I had never done student teaching. I was in home instruction in the first, second, third—I didn't go to school until the middle of the fourth grade. So here I was with a group of nondisabled children coming into my classroom, never having student taught. But more importantly, having absolutely no experience what it would be like to be in a classroom with seven-year-olds, because I had never been there.

I think they're kind of unique feelings. For me, they really just stick out as something that most people don't experience the same way.

Young: Most people don't experience the same sense of what, exactly?

Heumann: A twenty-five-year-old person, or twenty-three-year-old person, doesn't enter a second-grade classroom thinking, "I've never been here." In any way [chuckling], shape or form. You could certainly think, "Oh, I've never taught this class before." But not "I've never been in a room" because you were in most cases, at the age of seven, in school. So my fantasy is you think back, well, do I remember what it was like? Or I do remember what it was like. And be able to envision what it was like being in school when you were seven years old. For me, being in school when I was seven years old was, I think, in my bedroom with a table.

Young: It sounds almost like it was teaching in a foreign country, just a totally foreign experience.

Heumann: Well, yes. It was creating my own because since—which I know we'll get into later, but—because I had never student taught. I had no classroom experience. I had no classroom experience professionally or personally because I had never been in classes with nondisabled kids till high school. At all. That's a big gap, you know, never having been in regular classes. I mean, I was in school with disabled children from the middle of the fourth grade till the end of the eighth grade, but there the classes were small and the age range of the kids went up to twenty-one. So in my fifth grade class I had seventeen-, eighteen-, nineteen-year-old kids. It was just no parallel.

Young: You talked about things that you couldn't do: that you couldn't push yourself, you couldn't go up steps, you couldn't go up the hills. From my own experience, those were things that were often very difficult for me to say. Is that something that's developed over time, or even as a child could you speak very straightforward to someone? I can't do that.

Heumann: No, no. No, because at that time in my life, not being able to do that meant that I couldn't participate, so it was a very different experience, and it was typically a more painful experience that I would probably try not to replicate. You know, it was feeling like why are people making me do some of these things? It doesn't make any sense to me. Which probably was the way I felt when my father said I couldn't have the electric wheelchair.

Pre-Teen life with a disability

Heumann: I mean, I think I was very lucky that I had a lot of good friends in the neighborhood; it was a very close neighborhood. But the older I got, the more problematic it became.

Young: How so?

Heumann: Well, because as long as you lived in the neighborhood and as long as we were young, my friends could physically do things that I couldn't do, but it didn't really matter as much. It started to matter when the kids could go out of our natural environment more.

Young: They could also do things on their own.

Heumann: Could do things on their own, could go off the block, could go in a car and go visit a friend. To go visit friends off the block, because when we were younger we didn't really visit friends off the block that much. We went to family. I'm sure this happened, but I don't remember my friends going to parties for kids in their class. Of course they did, but I don't remember feeling badly about it because there were enough kids on our block that if one person would have been doing something—.

The other thing in my neighborhood is everybody didn't go to the same school. So I think one of the reasons why it had a different impact on me is because the Voehls went to parochial school and the Almskogs went to public school and these were my neighbors.

But, you know, one family went to Catholic school, one family went to the public school, and it was very mixed. So you had about a 50 percent; 50 [percent] went to Catholic school, and 50 [percent] didn't. But so there the kids who went to Catholic school didn't go to the same parties as the kids who went to public school, and vice versa. So you didn't feel badly about it.

Young: Because nobody was part of everything.

Heumann: Exactly. I was a part of everything on the block. So any birthday party on the block, any activity on the block, I went to. I mean, I was in Brownies, and I was in Girl Scouts, and in Brownies, the Brownie troop was not accessible. There were three or four steps to get in. The troop had their meetings in the chapel. My mother would pull the wheelchair up the steps. Then anything that went on inside, I participated equally. We played games. We just did things together.

So I remember things like pick up. You'd stand in two rows facing each other. You'd each be given a number, and they'd put something in the middle. You know, your Brownie

beanie or something. And call three, and the three's would have to run out together and pick up the Brownie beanie and whoever got back first won. Well, I couldn't do that by myself. But that was never an issue because somebody did it. So they pushed my chair out, and picked it up. I did everything.

It didn't feel like I wasn't doing it because it was just very natural. One year they went ice skating and said that I couldn't come because they took a bus and the wheelchair couldn't go on the ice skating rink. I remember feeling so badly because it was the first time that I had ever not participated in an activity in Brownies or Girl Scouts, whichever it was.

I definitely remember having to call my friends to come out, to come to the end of their steps and scream inside to see if anybody could come out and play. I remember not liking that. Or feeling a little bit weird, you know? Being out on the street screaming when everybody else would go up the steps and ring the doorbell. At that age, you know, you didn't use the telephone. You weren't calling up and saying, "Arlene, you want to come out?" No one suggested it. It was just go outside and see if so-and-so is home.

But I did go into my friends' houses, and either my family or their family would carry me up and bring me in the house. Because everybody had moved into this neighborhood pretty much around the same time, and the people who were living in the block had known me before I had polio, so it was just kind of a different experience.

Attendance in public schools and distancing from neighborhood friends

Young: Did you ever—or maybe a better question is—at what point did you channel energies differently because of disability? I think, from my own experience, my experience—

Heumann: You're too old. You were old enough when you got your disability that you were A) old enough and B) still young enough to be able to think about these things. But the truth is—

Young: But in the absence of sports, I did a lot more school than I had ever done before. I mean, did you do more with school than, say, your siblings did?

Heumann: No. I mean, really, there were things that went on in part because I was a girl, more at certain points than because of my disability. So for example, my brothers went to Hebrew school four days a week: Sunday, Monday, Tuesday—no, five—five days a week. The girls only went three. But that wasn't disability-related. My brothers worked in my father's store, but my female cousin didn't work in the store. Her brother did. The boys did; the girls didn't.

I mean, everything starts when you're older. I really do not remember much of anything until I went to public school as far as what I did during the daytime. I remember what I did when the kids came home: I went outside. I wasn't studying more because I had been just studying at home with my mother for, like, six, six and a half hours. There was nothing more to study. I didn't have any homework. I did my homework during the day. I read, but everybody in my family read.

I didn't watch a lot of television. We weren't allowed to. But it wasn't my brothers any more than me. We weren't allowed to watch television during the week. We had to get permission during the week. We had to get permission to watch television. So that was kind of all uniform.

Now, when I went to high school, that's when things really began to become different because in high school everyone went to a high school via a bus or somebody driving them. Now, it's true that I got driven to school also, but I knew that—I was adult at that point—and I knew that things that were going on were really wrong. So I didn't get to go to the high schools.

Young: What do you mean you didn't get to go to the high schools?

Heumann: Of the kids in my neighborhood.

Young: Oh, you went to a high school—

Heumann: Out of my neighborhood.

Young: I didn't know that.

Uncomfortable in high school

[Tape 2, Side B]

Young: Okay. You were talking about public high school.

Heumann: I always had a long way to go to school. Those were things that I didn't like. I mean, I always had friends on the bus, so it was, like, you just learned different ways of socializing. When I started going to school in the middle of the fourth grade, I was spending up to four hours a day on the bus. It was a minimum of three hours a day, but you could spend three to four hours a day on a bus. That's when things really were also different. When I was in home instruction, I wasn't with anybody during the day, then I was with my friends.

When I went to the public schools, I was making different friends, but none of the people in my neighborhood knew the people that I was meeting because whereas we had a neighborhood where you had 50 percent in parochial schools and 50 percent in public schools, the kids who went to public schools went to the same school, except for me.

Feeling different

Heumann: The experiences when I got older, when I went to high school, were much more difficult because I felt different. I think teenagers feel different in any circumstance, but I very much felt it. Actually, as we talk about it, not having a motorized wheelchair was a very big problem because I had to have people push me in school, and they had aides who would push you. In elementary school they would have the aides, but it was just the classes for disabled kids, and it was also a hallway. I could push myself up and down the hallway. It was a flat surface. That I could do.

Young: It's hard to feel cool if you've got a personal aide pushing you around.

Heumann: Exactly. You know, my fantasy is some people push themselves really smoothly and easily, so it didn't matter, but I couldn't do that, so I never felt comfortable in the high school, ever. I think I can honestly say I never felt comfortable in the high school. I always felt different. I always felt like I didn't really belong because I went from this segregated environment where what I had in common at least the classes with kids who had disabilities or who were being bused in. We all had kind of like a similar identity of sorts. Not personalities, but identity.

Then, in high school, it was you were going from classes of eight to ten to classes of thirty to thirty-five. Now, the only time that I felt comfortable in high school was the first year I was there. There was tracking in the schools in New York then. There was academic, commercial and general courses. I was taking academic courses.

Young: Can you say a bit about what the three were?

Heumann: Academic meant you were on college track. Commercial meant that you were vocational track. You know, secretaries, bookkeepers. You could go to community college and things like that. You weren't going to go to college because you weren't taking the same courses. The general track was for the dummies.

I was in the academic track. For the first year in high school, the special ed kids in the general course, you took all your classes in the homeroom, together, I believe. Factually, I know for myself if you were on the academic track, you took three courses with disabled students only, and two classes out. The two classes I took out were language and math. I took algebra and I took about one day of Spanish because when I went to the Spanish class, there were no disabled students in the class. The other two students who were on the academic track in my class, my freshman class, disabled students took French, so I un-enrolled in Spanish and went into French because I was afraid of being in the class by myself.

Now, there were thirty-some children. I clearly was not in a class by myself, but I clearly felt like I was by myself amongst all these kids. I didn't know any of them. I had no opportunity to meet them because at the end of our classes we left. The only class time that's nonstructured is homeroom, and homeroom we had with all the disabled kids. So the truth is in high school I would feel reasonably comfortable in the classes with the disabled students. I knew them; we were on the bus together; dah-dah-dah-dah-dah. I didn't feel comfortable in the regular classes.

Which isn't to say, at all, that the special classes are better than the regular classes, but it is to say that for me it was very difficult making those transitions. I think I felt very different when I was out of the environment I grew up in. My disability when I was younger, I don't want to say it didn't mean anything, because obviously it meant a lot to me and I

realize that my family was doing a lot more for me and my brothers maybe resented things that they had to do for me, or I felt that way.

When I was younger, I was already beginning to measure when to ask for what because I had to ask for so many things that, you know, I would be able to feel people not wanting to do certain things. So you kind of learn early on. Okay, there are three things you want, three things you need. What do you need now? What can you maybe give up on? What do you need of those three later? You began to think a lot about how to work your environment or manipulate your environment to be able to kind of ferret out who was into doing what and who wasn't into doing what.

So the high school was always uncomfortable, except for the homeroom time. I never dated in high school. I went to summer camp. That's something we can talk about another time. My experience of being in the disability community is that it's an emotionally qualitative different experience.

Young: Being in the disability community meaning having a disability or when being among people with disabilities?

Heumann: For me, having a disability, being amongst others who have disabilities.

Young: You have identified a whole bunch of stuff. Shall we stop for now?

Heumann: I think so. I'm tired.

III. Education, Summer Camp, and Early Activism

Relationship with siblings

[Interview 3: May 4, 1998] [Tape 3, Side A]

Young: Let me come back to a couple of things from last time. The first one is you mentioned really briefly that your brothers resented things about you. What kinds of things?

Heumann: Well, my brothers and I have never had this discussion, but I've gotten the feeling that as we got older, since I was the oldest, when I, for example, was taking voice lessons, and my father brought me into the city a lot, but if he couldn't do it, he would have one of my brothers do it. I've talked to a lot of my friends, and we all have—not all—but many of us have a similar experience about siblings who buy places that are not accessible and how we feel really badly about—

[tape interruption]

Heumann: You feel really badly about how—you know, why? What is the statement that is being made when a brother or sister buys a house that you can't get into?

Young: If anybody would think to, you'd think that your siblings would.

Heumann: Yes.

[tape interruption]

Heumann: So there just has sometimes been that feeling, like that they had responsibilities to do things for me that they wouldn't have had if I didn't have a disability. That's just been a feeling I've had.

Then my one brother has a place that is pretty accessible. They built the house. My other brother had a house that wasn't accessible, another house that was accessible, and the newest house is very inaccessible, so that's—

Young: It kind of went from bad to worse.

Heumann: Yes, when I had polio, my mother was nine months pregnant with my brother, so I was in and out of the hospital for a year and a half right at the time he was born. So I'm sure that while my parents always did their best to divide their attention, my mom was still in the hospital visiting me a lot after he was born. Even when I came home, I needed a lot more help. So I'm sure all that's there.

Continued dependency on family

Young: You said that you had to think about what you could ask for, what you should ask for in ranking things of importance. Can you give some examples or talk a little bit about what kind of impact that had on you?

Heumann: Well, I think my mother was the provider for myself and my two brothers as far as what the mother's role is: the cooking, the cleaning, driving you here and there, and doing all these different things. But as each one of us got older, my brothers were able to assume more responsibilities. I still needed help with getting dressed, going to the bathroom, everything, and my mother had three of us to get out the door.

For example, sometimes she would just take out the clothes that she wanted me to wear, which would really annoy me, because I couldn't get to the closet myself. They'd been given bad advice by the contractor. When I had polio, they decided to expand the house out, and they put a bedroom and a bathroom on, but the bedroom was too small so that there wasn't enough room for the wheelchair to go to the closet. So my mother would just go in and take out what she wanted. If I didn't want to wear what she wanted me to wear, well, that turned out to be a fight, because, "I don't want to wear that." Well, you're separating yourself at that age when you're in high school, and, you know, kids *can* go into the closet and get their own clothes. I couldn't do that.

If I wanted to go someplace, if I wanted to go outside or just whatever it was, if I needed help to do it, it meant that I had to ask somebody to do something. Of course, they were most of the time doing their own thing, no matter what it was, and so they would have to stop what they were doing in order to help me with what I was doing. So that has always felt like an intrusion.

When I'm paying people, it's a lot better; although, even there, if people are resistant to doing what they're being paid for, it still means that I have to be more assertive, but at least I feel like I'm paying somebody for the service and so—

Young: It's not a favor.

Heumann: Exactly. It's not a favor, which is a whole other set of issues about when is a friend a friend, and, you know.

But, so I think those were some of the issues. You know, feeling badly when people would say no to things that I knew that I—if I didn't have my disability or if the environment was accessible—I could do without asking. Even the ability to get into trouble was limited because I couldn't. [laughs] Clearly, there were a lot of things I could get into trouble with, but there were things that I couldn't do, couldn't do the same kind of exploring or—

Young: I hadn't thought about the trouble part, the separation part, that even to do something like wearing clothes to kind of get in your parents' face in some respect, they still had to kind of help you to do it. That kind of really undermines the whole idea that you do something—

Heumann: My mother never wanted me to wear pants. She used to say, "They're too hard to put on with your braces," but the truth is my mother doesn't like pants on girls and women. I don't think she really minds it anymore, but she never wears them, and she only wore them once in a while for really, really casual things. So if I would have been able to go out by myself, I could have gone out and bought my own pants and put them on. So we would have had a fight about it, but that's kind of a normal thing to do.

Young: Did you ever win the fights over clothes or whatever?

Heumann: Oh, sure, sometimes, but it was an unfortunate tension, I felt, that went on. I mean, it wasn't like an overall, pervasive tension, but it did make me realize that there were different things that I had to balance.

Young: Did this—your need to kind of think of this thing or that thing—did that mean that needs went without being met, that things that you maybe really did need, you still felt like—

Heumann: Essential things never went undone—you know, going to bed, getting up, going to the bathroom, eating, doing all those kinds of things—that never went undone. But, you know, what is essential to a teenager? It goes beyond that. So it's really why I encourage families to start using personal assistants, if they can afford it or get money for it, as early as possible, because you really want to be able to have a way of having some natural divisions. One of the things that you want to be able to do is also learn a level of independence and autonomy, that you're really learning if you don't have a disability like mine.

Young: I hadn't thought about that, but that makes a whole lot of sense—it gives a person that tool to learn independence.

Heumann: You do learn earlier to be a manager. It also enables the parents to begin to separate, because that's the other thing that goes on. Because when a parent has to continue to provide support of a type that they wouldn't be providing if their child didn't have a disability, then I think it also causes some of the issues around separation and overprotection.

— 34 —

Life in special education classes

Young: I'm going to make a little bit of a jump and go over to some of the experiences in school. I talked to Neil Jacobson for quite some time.

Heumann: Oh, really?

Young: He told me some good stories about you and PS 219.

Heumann: He's got a good memory.

Young: He described you as "a political dynamo."

Heumann: He was five! [laughter]

Early activism

Young: Talking about you organizing from the earliest days that he remembers. He described you getting people together to talk about ways that you could better get what you all needed, and he was telling me about some really early examples of activism.

Heumann: I mean, I think I remember that in the program that we were in, after lunch period we had a rest hour. It didn't matter how old we were—and these kids went up to twenty-one in our program—there had to be a rest period. [laughter] I do remember talking about how ridiculous it was, and talking with the kids about it. Of course, there was nothing that you could do when you're ten, eleven, and twelve, but we were talking about it.

We also were talking, even at that point, about how we felt, having disabilities: how we felt different, how we didn't understand why we were being treated differently. I remember my mother did organizing, you know, working with parents and trying to improve what was going on in the classes and getting the board of ed to open up some schools so that we could go to high school if we were in wheelchairs. I used to feed a bunch of kids at once. I was always hyperactive—not hyperactive—I needed to do a lot of things.

Young: He said you were a very rowdy kid.

Heumann: [laughs] Uh huh? Maybe he was very passive. [laughter] I mean, I was never a passive kid. I think when I was in an environment with other disabled kids, I definitely felt more comfortable. I think we went to camp together, Neil and I, too. You know, I was always more outgoing in those environments.

Young: Now, you said you got together and you would talk about how you felt about disabilities or about your experiences. Did you find that your experiences were quite similar, that you felt like you shared things in common? You know, because normally there are a variety of disabilities represented.

Heumann: Oh, yes. No, we definitely—*I* definitely did. The fact that we were all in the same program meant that we shared something, because none of us were going to our neighborhood schools, and all of us were driving these ridiculous amounts of time to get to school. I think I felt more valued than the kids who were older in the program. Clearly, when I was ten/eleven, there were kids in the program who were seventeen, eighteen, and nineteen, and they were kids, particularly, who had cerebral palsy and speech disabilities. Neil was another generation, really, when he came into the program, because, had he been ten or twelve years older, he wouldn't be where he is today.

Young: Because they weren't taking the time to work with speech or to do classwork?

Heumann: No, because there was no expectation for kids to graduate. I mean, this was a public school where everybody left in the sixth grade, except if you were disabled, and then kids stayed there until they were twenty-one, and then they went to shelter workshops.

Young: Oh, so it was just sort of a holding ground, not really a progressive, developmental ground?

Heumann: [laughs] "A progressive, developmental ground." You're cute. [laughs] *No*, I don't *think* so! Nope. No, there was no expectation.

Creating a disabled movement

Young: Neil said, quote, "I grew up with the disabled movement mentality, even though there was no disabled movement." What exactly do you think he meant by that, and would you say the same for yourself?

Heumann: No, Neil was always more of an outsider. He kind of didn't really blend. So I think I could see him feeling like he grew up feeling that way, because the movement evolved. I mean, given the fact that we didn't know anything about the history of what was going on in the disability community across the world when we were growing up, we were kind of not even knowing, but we were creating as we were going. So we were the movement. Do you know what I'm saying? We weren't waiting for somebody else to create the movement that we would be a part of; we were creating. We knew it. I mean, I knew it, and my friends who were active in what was going on—we knew that we were creating something different.

Young: Well, I'm thinking there may have been a time when you didn't think in movement terms, but you were doing movement type things. Would you say that that idea of creating something came pretty early?

Heumann: Yes, I think it's true. You have to realize the time that we were living in. I mean, in the time that we were living in, there were a lot of movements. So it's true that when I was six years old I had no idea, when I was nine years old I had no idea, but when I was in college—well, we knew that we were doing something different because people were giving us a response, either yes or no. There were things that were going on. I think we really started doing a lot more work toward the end of the sixties when some of my friends and I were searching out that we weren't satisfied with what was going on. That we were at a point in our lives when we were realizing that we weren't going to have the same opportunities that other people were. That the environment around us was both physically inaccessible and the people around us didn't seem to share our ideals and our vision of what needed to happen, because they were talking about why what we wanted couldn't happen or was too expensive or we had to wait or whatever it was. Even at an early age we knew that we were doing something different, and maybe we didn't call it a movement in the sixties, but we definitely knew that we were change agents, because people responded to us: disabled people responded to us in positive ways and nondisabled people responded to us in negative ways.

So, you know, with the women's movement, with the African American movement, with the antiwar movement, there were very similar parallels: people who agreed with you supported you, people who didn't agree with you, didn't support you. You began to see that authority figures were more likely <u>not</u> to support us, and family members and disabled people were more likely to support us.

I think part of the issue was, since we were creating it as we were going, it was as much for us to overcome our own personal limitations about what was right and wrong, because I grew up in a community where demonstrating wasn't something that really happened. My parents had questioned authority, but it was something that didn't come naturally. I mean, it did, over time, become natural because my mother and father learned that if you didn't challenge, you didn't get. So, for me, that was something that I had learned when I was younger. You know, I wouldn't have gone to high school if my mother hadn't organized the parents. That's the only way we got to go to high school. But I always felt like I couldn't be an observer; I had to be in the middle of it, just because of who I was.

Young: That rowdy kid that you are.

Heumann: Yes. [laughs]

Importance of education to parents

Young: Your mother really took education seriously, and—

Heumann: My father, too.

Young: —wanted to find as many educational opportunities as possible, and one of the examples that she described was vacation bible school, that she wanted you, since you weren't getting the classroom experience in—

Heumann: Oh, is that why she set that up?

Young: That she wanted you with nondisabled kids and the classroom experience.

Heumann: Right.

— 37 —

Young: A lot of kids just think school is the worst thing. I mean, were you ticked off at your mom because she kept trying to put you into school or were you really with her, thinking that this was a good idea?

Vacation Bible school

Heumann: Vacation Bible school was not school. It was a summer program.

Young: Right.

Heumann: There was a lot of singing and recreational stuff, and kids like being with kids. I mean, I enjoyed it. Otherwise, what do you do? You stayed at home. I was young. I probably was less than nine.

Young: Well, she described a really interesting experience in that case, that this minister sort of went out of his way to do everything that he could. And your mom described one instance where—I'm forgetting the detail now—but there was some portion of a day that—

Heumann: And she told him I didn't need to go there, and he—

Young: And he kind of—

Heumann: And that was her way of also setting limitations.

Young: She said, "If Judy's going to be a part, she's going to be a burden."

Heumann: Mother might have been saying that carrying me would have been unnecessary. [added during editing: My recollection was that my mother wanted me to be included in the Bible school program and felt it was not important for me to be carried downstairs as only a brief activity occurred in the basement. She worried that if it was too difficult, people wouldn't want me back. Pastor Topper (I believe) understood that I needed to be a part of the group the entire time. Parents straddled a fine line—always worrying about exclusion, pushing for inclusion, few role models or peers they could talk with.

My mother told the minister he did NOT have to carry me up and down the stairs. He felt it wasn't a problem. I know my mother was happy that he did carry me even though she said he didn't need to. She would speak about the minister and how nice he was.]

She said I was a burden, so I thought of things as burdens, too. You know what I'm saying? You kind of accept. Even though she definitely pushed on things, there were certainly areas where she didn't push beyond.

So it was inconvenient for him to do it, or he didn't have to do it, and they weren't down there a long time and it would have been all right, but he was a very nice guy, because he understood that everybody is going, and if I don't go, that's very weird.

— 38 —

So I think there is this feeling amongst parents that you don't want to be a burden and your kids will adjust.

There was, I think, a feeling based on the program that I had been in, the special ed program, that from the very minute you got into the program you were screened. The parent had to go to school with you for a week, you had all these assessments, and they actually voted on whether they would accept you in the program. I don't think there was anybody who was ever necessarily not taken, but there was always the sense that they didn't have to take you, and if they wanted to get rid of you, they could. There was no reason to believe that wasn't true.

Young: I presume that you began to guess that's the way it works everywhere, so he must have surprised you with his eagerness.

Heumann: I think I was too young to—I mean—

Young: That's true.

Heumann: The truth is, it wasn't a big deal for him to carry me up and down the stairs. My father carried me up and down the stairs all the time, so I didn't think anything of it. I think if it would have been a woman I would have felt differently, but it didn't seem like any big deal to me.

Young: The experience at Hebrew school, also, seemed interesting, because maybe the argument in the public school system was that you couldn't integrate these people with disabilities into the rest of the classroom, and yet it seemed to work quite well at the Hebrew school.

Denied Yeshiva experience

Heumann: It was an after-school religious program, so it was like we went there three times a week. Yes, you never thought anything about it. <u>But</u> when they tried to get me into an all-day Yeshiva, I didn't get accepted.

Young: Oh, she didn't tell me that.

Heumann: Oh, yes. What happened was my parents decided that since I wasn't getting into public school, they would try to get me into a Jewish day school, which is not what their first choice had been for us. They wanted us to go to public school. So my mother found this one program. When I was going into the first grade, I was going to be six, and the principal told my mother that I didn't speak enough Hebrew, and that I couldn't come into the program because I didn't speak enough Hebrew. So my mother had me tutored, like almost every day, by this native-born Israeli woman. And then—

Young: You spoke better than him.

Heumann: But they didn't accept me into the program. When my mom called back and said, "You know, you wanted her to learn Hebrew," then he said, "Oh, it's just not going to work."

So, but then there was another Jewish day school that was opening up, but I was in the second grade, and they were adding on a year at a time, so I was going to have to go back into the first grade. My parents decided that they didn't want me to go back to the first grade because I was doing work above second grade, and they thought that it would be holding me back too much. So I didn't go there either.

Entrance to Hebrew school

Heumann: But, no, there wasn't any difficulty in that. The first Hebrew school that I went to was in a synagogue that we went to, and it was all relatives, so no one would deny me coming in. It was all family. Then the other one we went to was in the neighborhood where my father's store was. So, you know, you paid your money, and my mother brought me there and picked me up, and that was that.

Young: With the Hebrew education, the classes—was that very important in sort of developing who you are?

Heumann: It's funny, I didn't feel uncomfortable in those classes, because, in part, they didn't feel as competitive. I mean, you got a grade, but it wasn't the same thing.

Young: You did get grades?

Heumann: I think we got grades.

Young: I was thinking it was like the Christian Sunday school where it's just kind of, you know, you talk about stuff. So there were actually—

Heumann: We took Hebrew classes. I mean, you learned Hebrew. We didn't learn Hebrew that much, because it was only a short period of time, but that's where I learned to read Hebrew, was in Hebrew school.

[Tape 3, Side B]

Young: Not just in regards to disability, but in terms of your religious identity, I know you talked about synagogue at least at varying points in your life playing a pretty important role. Were these Hebrew schools—was that a pretty good thing for you as far as—

Heumann: Oh, yes. I liked my religious experience. I mean, I think it was very clear that Judaism, well, I mean, religion is people, so there certainly are some Jewish people who discriminate against disabled people, just like everybody else. But in the environments that I was in, because they were so closely knit to my immediate family, I always found it to be an important experience for me, a social experience. You know, I'd go to synagogue, I'd see my cousins and my friends, and so more often than not I liked it.

I think, as an adult, being Jewish is an important part of my life because I think of what happened to my grandparents, and the customs and the traditions are important to me.

[tape interruption]

Attendance at summer camps

Young: You talked about camp as being really important in terms of your childhood. Tell me about the camps you went to.

Heumann: I went to two. Well, actually, I went to more than two camps. I went to two overnight camps: Camp Oakhurst and Camp Jened. Then I remember I went to some summer camp run by a community center once, I think, which was with disabled and nondisabled kids, but the other sleep-away camps that I went to, the campers were all disabled.

Young: Was this like a week-long camp?

Heumann: No.

Young: Or a whole summer?

Heumann: Camp Oakhurst was three weeks, Camp Jened, you could go four weeks or eight weeks. I did both over the course of the years. I guess when I was a junior in high school I didn't go to camp because I failed chemistry. You know, I'm not sure about that. Maybe it was when I was in college that I didn't go to camp. But I went to camp from the time I was nine until, I think, I was a freshman in college.

Young: Wow. Did they group age ranges, or was it kind of like a public school, with everybody together, all the ages?

Heumann: No, the bunks were age consistent.

Work at camp

Heumann: I'm trying to think. I worked at the camp one summer, and I think it might have been in 1969 or 1970, after I was out of college, I think.

Young: That you worked there?

Heumann: Yes, and that was unusual, because the camps usually didn't have disabled people working there. The counselors were nondisabled, and the campers were disabled.

Young: What kind of dynamic did that create?

Heumann: Well, when you were younger, you really didn't see it as much because there were counselors and campers, but when you began to get a little bit older and you were fifteen and sixteen years old and were a camper, and the people working in the kitchen were fifteen and sixteen years old, then you did begin to say, "Hmm, how come we don't have those jobs?" I don't think we said it all that much out loud, but there was definitely this feeling that there were these spoken and unspoken rules.

Freedom at camp

Heumann: I think why I liked the camp a lot and why friends talked about liking the camp a lot was, one, we were away from home, and you know that was true for most kids. They like being away from home. But, in addition to that, I think, we weren't as restricted because we were away from home. We didn't have the same rules—which, again, I think, is typical for any kid. Also, our friends were all in the same place. If you were home and you wanted to go visit a friend, someone needed to give you a ride to get there, and that would make it more difficult to get there. Or, maybe a friend that you wanted to go visit—their house wasn't accessible, so you couldn't get in. But here it was like everything was just there, it was just easier to get to. Also, dating was something that started pretty early on, and a lot of us didn't date when we were home. So people had relationships when they were in camp, but when they went home they didn't have relationships, I mean, dating kinds of relationships.

Young: Did staff encourage that or discourage that? Or were they kind of indifferent?

Heumann: I went to two camps that were not repressive around things like that. So it wasn't like they encouraged or didn't encourage, it just was there and people accepted it. You know, depending on the counselors, I'm sure they encouraged it about the same level you would have seen going on in other camps that allowed that type of stuff to go on. But I know for some—I think a lot of us—it was really a very important part of our lives. We talked favorably about it. I think camp was more important to me, probably, than to my brothers, because I don't recall them talking about it that much, and they didn't go as long as I did because they started working.

Young: It sounds like it would almost give a rival vision of social order that you could envision that life could be better by the accessibility and the openness to dating and other examples that maybe gave you a little bit of a charge for wanting to change the world out there.

Heumann: Yes, and I think there was also an opportunity, again, for us as we got older to talk about, because you were together with people for at least three weeks, four weeks, eight weeks, so you really did get to talk about things in a more in-depth way. Just regular teenage things, as well as personal and feelings and things like that. So I think that was always very helpful.

Young: What was the daily life of camp structured like?

Heumann: Did you ever go to camp?

Young: Well, I kind of had some bad experiences in camp because I went to a religious camp.

Heumann: Well, you know, you got up to somebody making a noise of some kind, usually, and got dressed and went to breakfast and came back and cleaned up your room—or bed because we were in a shared room—then you had different activities. Sometimes you had swimming, you'd have sports, you'd have, whatever, arts and crafts, drama. It was camp. We had lunch and rest period [laughter] and then activities again, and dinner and activities at night.

Young: Were the people at camp pretty progressive? The staff? Or did you experience a lot of paternalism there as well?

Heumann: No, the camps that I went to, the staffs were college students, and they were, as a rule, pretty cool. I don't really remember feeling that the counselors treated us much differently because we had our disabilities. They were the camp counselors. It didn't feel oppressive at all.

Cross-Disability camp attendance

Young: Did these camps have representation from the whole variety of disabilities?

Heumann: One of the camps that I went to did. Camp Jened did. They had mainly physically disabled individuals, but they did have some blind people, and some deaf people, and multiply disabled people, and some people with mental retardation. That Camp Oakhurst that I went to was primarily physical disabilities.

Young: There or in school, did you feel more naturally drawn or attracted to people with certain types of disabilities than others, or did they all seem kind of the same to you in some way?

Heumann: What do you mean, "attracted to?"

Young: Were you more likely to become friends with people who had polio, or just as likely to hang out with people who were blind or had cerebral palsy, whatever?

Heumann: I didn't know that many blind people because in the school I went to there weren't any blind people. In the camp that I went to there were a few blind people. You know, I was drawn towards people that I could talk with, but for that, for me, it didn't matter if people had speech disabilities because when I went to elementary school, I went to school with kids who had cerebral palsy and so it was just like kind of normal for me. No, it didn't seem unusual, any more unusual than the whole thing was unusual.

Awareness of hierarchy of disability

Young: A lot of people talk about the hierarchy of disability. Is that something that you, if not felt, witnessed or experienced?

Heumann: Yes, I mean, I think I definitely remember feeling it when I was in elementary school. In the fifth and sixth grades they would select a certain number of students who were good students, and they would be able to come down and help us get our coats off and do different things like that. That's when I would realize that the nondisabled kids saw us differently in the class. So the kids who had cerebral palsy were treated differently by them. I was definitely aware of that. We didn't see them very long, they would be there for fifteen, thirty minutes at the most, but those of us who had disabilities like polio or muscular dystrophy were more likely to be the ones that they conversed with than the kids with cerebral palsy. So that was something that I definitely noticed.

I think the more nondisabled you are, the more opportunities you have, just because you can get around and do things. On the other hand, I've also felt that people whose disabilities appear to be less significant sometimes have more significant emotional problems than people who have more significant disabilities.

Young: How so?

Heumann: Well, not being one of them, this is just my speculation.

Young: That's okay.

Heumann: My speculation being that you're almost there, but not quite, and that people with more significant disabilities don't necessarily accept you either because you can do so many more things than we can do, and nondisabled people don't accept you because you're not nondisabled. So you're kind of neither in one world or the other and trying to figure out an identity. My feeling was that people who had less significant disabilities couldn't easily decide, "I want to be here," or, "I want to be there." Because they really wanted to be with the nondisabled world.

Young: Good perception, speculation. You said you never dated in high school. How about at camp?

Interracial dating at camp

Heumann: Oh, I dated at camp all the time, but I never had a date in high school.

Young: Any stories you want to share with the public?

Heumann: About my dating? Oh, well, you know, just the general. You know, at camp you were kind of not "in" if you didn't have a boyfriend, and I had a boyfriend from the first year I was at camp.

The thing about the camps was they were also racially integrated, just like our schools, which was, of course, very different than what was going on. I mean, our special ed classes were racially integrated in a school that was basically almost 100 percent white. While my brothers went to camps that were white, I went to camps where we were everything.

— 44 —

Young: Was there a lot of interracial dating?

Heumann: There definitely was. I mean, my first boyfriend was a Puerto Rican guy. My friend Carol actually wound up marrying a guy who was an African American. Yes, people had relationships based more on who they liked.

Young: Do you think maybe because people with disabilities, by experience, learn more to look past the skin, the sort of bodily differences, that they were more adept at race issues?

Heumann: To a degree. I mean, we went back and lived in our communities that were pretty segregated, and so we had different experiences than our family members, positive experiences that family members didn't necessarily have, because they didn't necessarily have *any* experience. But I think you learned on the face of it that your friends were your friends, but you also learned that there were some subtle divisions that went on.

More on hierarchy of disability

Heumann: I want to say one other thing. I forgot that one of the camps that I didn't go to was a camp called Camp Corolla. Camp Corolla had summer camp, but then they also had weekend activities all year round. The woman who ran the camp was a woman who had a mild disability. I used to go sometimes to their Saturday programs, but there you saw the hierarchy was very much in place there at that camp.

Young: More so?

Heumann: I felt very much like I was not a part of the hierarchy. Of course I think it was in part because the kids who went to camp in the summer and went to programs over the year knew each other more than those of us who came from the outside and only came in on the weekends. I think, well, it wasn't just those with less significant disabilities because some of the people who were in the in-crowd had less significant disabilities.

But, yes, for me, whenever I was around disabled people, it felt and feels more comfortable. You know, being attracted to other people was just something that I assumed is more like what nondisabled people do, because you didn't have all these questions, you know, disability/nondisability-related questions. There were more, What's he or she like? Would I like them? Would I not like them? Are they too disabled, could they help me with what I really needed? You know, those. It did get into disability stuff sometimes, too, but it wasn't as much, I think an aversion as a practicality kind of an issue.

Young: In regards to dating, you talked about the power chair when you were twenty or eighteen or nineteen. When did you get the chair?

Heumann: I think I was a senior. I either got it at twenty or twenty-one.

Young: Okay. That would be the first time that you were able to get out and be about by yourself. What was dating like in camp?

Heumann: You mean without having the motorized chair?

Young: Or not necessarily the chair, but—

More on dating in high school

Heumann: Dating in camp is different. You know, it's like you sit next to somebody at the movies, you dance with them at a dance, you kind of go hang out with them on their porch during rest period. [laughter] I mean, it's different. The environment, the area in which you have to deal with is a much smaller geographical area.

One summer I had this nondisabled guy as a boyfriend. He worked in the kitchen. What is his name? Then I remember he went into the navy, and he came back and visited me one summer, one time. Bob Skirmack or something like that. I did have a crush on my counselor who wasn't disabled. I remember thinking, "No, he's not disabled. He wouldn't be attracted to us." But, you know, then of course we were campers and he was a counselor, and campers and counselors didn't go out together. But my friend Carol did start going out with one of the counselors.

Young: That must have made quite a story around camp.

Heumann: I'm trying to think. It might have been while we were at camp when she was older—sixteen, seventeen. [laughs] But I never dated in high school.

Young: Why not?

Heumann: Why not in high school? I don't know. I didn't live in the same neighborhood as the school because we were bussed. So we didn't get an opportunity to really meet people the same way, and I never felt very comfortable, you know. But I think one of the big issues was there really wasn't an opportunity to really socialize, because the only non-structured time during the day was in homeroom, and homeroom was just with the disabled kids. I never felt really interested in any of the disabled guys.

Young: So did your bus pick you up right after school ended?

Heumann: Right.

Young: So you didn't have the option to get involved in any of the extracurricular activities?

Heumann: No, I did for two years get involved and sing for a class production, and then my mother would pick me up after school and take me home.

Young: That really does impinge upon the social life. And the clubs, the different clubs, those are really the primary way, often, that you get to know people.

Heumann: Nope.

Feeling uncomfortable in high school

Young: What sort of accommodations were necessary in high school? Did you have an attendant at that point while you were in school?

Heumann: I think then there was an aide there who would help us. I'm trying to remember. I don't really remember that much, but I know that there was. I don't remember the name of the person, though. Sometimes my friends would help me.

But in high school I just remember mainly not feeling that comfortable. I don't think it was an all-out consuming feeling because when I came home on the bus I was with my friends, and I certainly had friends who were part of the special ed class, and we socialized after school and talked on the phone a lot. Then I had my friends who I'd made in elementary school, and I was still friends with them throughout high school, and I had my friends in my neighborhood and my family. I had a lot of friends. I always had a lot of friends.

Young: It sounds like most of your best friends were people with disabilities.

Heumann: No, and friends from my neighborhood—none of them had disabilities. So, my friends in my neighborhood—none of them had disabilities—my cousins didn't have disabilities, the kids that I met through religious school didn't have disabilities, and then there were my disabled friends.

Young: Do you think there was a reason besides just not being involved in the extracurricular activities that you didn't feel more comfortable with nondisabled people in high school?

Heumann: Yes, because we never had time just to be. I think if there would have been time just to kind of hang out, a neighborhood. I mean, everybody in my neighborhood was nondisabled.

Young: You were feeling comfortable in other nondisabled environments.

Heumann: Exactly.

Competitiveness of regular classes

Heumann: I think one of the things that went on in high school, one of the very big issues, was that it was competitive. I had been on home instruction until I was in the middle of the fourth grade, and then I went into these separate classes which were non-structured and not a lot of academics going on. I was smart. You know, I have no idea how I learned, because I wasn't really given much instruction, but when I was doing testing in the fourth and fifth grade, I was reading at a twelfth-grade reading level and things of that nature. So I did a lot of reading at that time. But when I got to high school, when I took the classes with the disabled kids, then I didn't feel nervous, the classes were small. We had the regular curriculum and were being tested on it, but I didn't feel as nervous as I did in the regular classes.

Young: How did you do in high school with grades?

Heumann: My grades were in the eighties, I think, right between, depending on the course, but my average was probably something like eighty-six to eighty-eight overall. Then there were a couple of courses that I took—

[tape interruption]

Heumann: I took stenography, typing, and business law. I loved those courses. They were great. I got, like, ninety-sevens, ninety-eights, ninety-nines.

Young: Did you use any aids to type?

Heumann: No, I was a good typer. I never felt uncomfortable in those classes. Those three classes. Again, I don't know what it was. Maybe the typing and stenography were different types of courses. There you learned to do it, and it was very tangible, we could do it. You could type, you could type accurately, you could type fast. You could do your stenography, you did it well, you did it fast, you did it accurately. It was kind of very clear, but when it got into the more abstract, I think it was both the issue of abstract and, you know, like in English and math I hadn't had a lot of the framework for it. So I remember being in classes as they were reviewing what people had learned.

Young: You said, "Wait a minute! I never got that."

Heumann: Well, no, but that was right. Then I would get really nervous.

Young: And you don't want to admit it.

Heumann: Right, what was I going to say? Exactly. So I always felt like I was struggling to learn it.

Test-Taking nerves

Young: Did the teachers treat you much differently?

Heumann: I don't feel like the teachers treated me much differently, no, but I remember my parents came home from open school night once and said to me that almost to a teacher had said, "Judy comes to school, she does her homework very well, she participates in class very well, but when she has to take an exam she always looks very nervous." I selected graduate schools based on schools that didn't require me to take a graduate exam.

Young: But it doesn't sound like you, somehow. Why the nervousness with the tests?

Heumann: I don't know. It's the grading, it's the competitiveness, it's feeling very insecure about getting a wrong answer. But I think it really is because I wasn't prepared to do it. I mean I was in such an unstructured environment for so long. My family, you know, we had a very verbal family where we talked a lot, we interacted a lot, we were pretty aggressive in expressing our views. Definitely we had lots of debates, and that I didn't feel insecure with, but there's just something about the final analysis of, you know, taking these tests that I've never done well on.

Thoughts on cutting slack

Young: Feel free to roam off your personal experience here on this question. In talking with other people—you know, I'm talking with a lot of people now—you get the sense that in different school environments people will "cut slack" for people with disabilities. [pause] They'll try to pave the way a little bit, but then end up doing a real disservice down the road because then you don't learn some of the skills that you need to be out in the competitive business world. Do you have any thoughts about that?

Heumann: Oh, I mean, I think it's definitely true that—speaking for myself—there wasn't any slack to cut in elementary school. [laughs] I mean, there wasn't much there.

[Tape 4, Side A]

Heumann: I mean, I think the other thing that was also going on in high school was the fact that I didn't—you know, we said this earlier—but I think the fact that I didn't have a motorized wheelchair had a very big impact on my ability not to feel independent and to feel self-conscious. I'm trying to remember about the aides that they had there, because I remember, you know, going to the bathroom was a problem. So there were always all these other things that were going on that never made things exactly right.

But I don't ever remember any of my teachers grading me higher. No, I don't. I don't ever remember feeling that way. I do think it's very true that sometimes teachers pass kids on—it's not just disabled kids—for whatever the reason. At that particular time it's not a good idea to hold kids back because holding kids back is considered to be a stigma.

But I think to me it's more the issue of watering things down. So if you were in special programs, it was much more likely that your program was not equivalent to the program that the nondisabled kids were learning from. I think it's more problematic when you're in those programs. When kids maybe are being graded differently and people don't know it. I mean, families have told me, "I thought my kid was on the honor roll. Well, it turned out they had a special ed honor roll." The family wasn't told that it wasn't the regular honor roll. But I think, as I said, when I was in school, it was more the issue of kids not being given opportunities, rather than cutting them inappropriate slack. It is a different time now. But the kids that I went to school with who went to shelter workshops—nobody cut them any slack.

Young: That's kind of what I meant, maybe cutting slack as to not giving them the opportunities.

Heumann: No, "cutting slack" is the right word. I think not giving opportunities and cutting slack—they're different—but I think they are both things that can happen.

When I taught the eighth grade class, the first year that I taught, I was in special ed classes, the same ones that I had gone to school in. Now, when I went back to teach there, kids no longer were kept there until they were twenty-one years old. That had ended. But I remember saying to the kids that it did feel like the teachers were, again, not cutting them slack, but not doing them justice, because nobody was requiring that they teach to the same standard that was being taught for nondisabled kids. I very much remember talking to the disabled kids in the eighth grade and saying to them, "You know, you're not doing yourself a favor by not pushing yourself and challenging yourself and working as hard as you can, because when you get out of this program and go into—" because then everybody went to regular high school, and so—

Young: The rules changed.

Heumann: The rules changed very dramatically.

Expectations after high school

Young: Did you have strong aspirations about what you wanted to do in high school when you grew up?

Heumann: No.

Young: Do you think that was different than your nondisabled peers?

Heumann: Ah—

Young: Were people not encouraging you as much?

Heumann: You know, when I think about my friends, I mean, when I was growing up in the sixties, I went to college. From my close friends in my neighborhood—my friends Arlene and Mary—they didn't go to college and they weren't disabled. There were a couple of kids in my high school that I was closer friends with who were in the special ed program, but one had a heart condition, and one—. No one ever exactly understood why Mimi—Mary Coyle her name was—why Mimi was in the special ed program except that somebody might have felt that she was a bit fragile. My mom would always say, "Why is Mimi in this program?" But she was a good friend of mine. She used to do Irish dancing and she came from a really big family. I went to a few practices with her and her friends. What was your question again?

Young: What kinds of messages you were getting about career opportunities—

Heumann: Oh, career. So, yes, so—

Young: —that maybe your nondisabled peers were thinking about it more because they were encouraged, whereas you were not.

Heumann: I mean, actually, really, as I look at myself and my nondisabled peers, as I was saying, my male cousins, all of them went on to college, but my female cousins didn't all go on to college, and in my neighborhood not all of my girlfriends went on to college. So, on a certain level, I was going on to college more than my peers were in part because the message that I was getting is, "Don't expect to be able to get married and have a husband who is going to take care of you. You need to be able to support yourself, and you aren't going to be able to support yourself on a high school degree. So you have to go to college." That was just something that always was expected. I mean, I think education was something that was very important to my parents. Their job was to work and take of us, and our job was to go to school and get good grades. I remember in the neighborhood kids would get money if they did good on their report cards. We never got money on our report cards. It was expected that we get good grades. If we didn't get good grades, it was like, "Why didn't you get a good grade?" The teacher was always right unless you could prove the teacher was wrong. You had to work really hard to prove that the teacher was wrong. But that was true.

IV. Reflections on the Disability Experience

Encouragement to attend college

[Interview 4: May 8, 1998] [Tape 4, Side B]

Young: Judy, when we were talking on Monday, toward the end you mentioned that people—it may have been your parents—communicated to you the idea that you shouldn't expect to get married and have somebody to take care of you, that you were going to need to get a decent job to take care of yourself.

Heumann: I don't know if it was expected that I shouldn't. It was changing, but it hadn't changed yet when we were in high school. Two of my closest friends didn't go to college. They graduated from high school, and they got married pretty much after high school. One of them never had a paid job to this day; they volunteer, and the other one didn't start working until she got divorced. So my parents' comments were, "You can't assume that you're going to—"

Young: Right.

Heumann: I know that it was related to disability, but I've never even asked my mom about it, even if she'd remember it. But it also probably really had to do with the fact that my mother also wanted me to go to college. So I don't know. But definitely it was somewhat disability related.

Young: Did they say that explicitly?

Heumann: It was—

Young: I mean not that it was disability—

Heumann: What they said explicitly was that I shouldn't assume that somebody else was going to be able to financially take care of me, and that I needed to be able to pursue employment that would pay me sufficient money to be able to cover my costs, which were more extreme than other people's. So you had to go to college in order to be able to get a degree that could earn you a salary that was enough.

Young: Did you take offense at that?

Heumann: No, I didn't take offense at it. No, because there certainly were women around me that were going to college. I did have friends who were going to college, and the guys were all going to college, all of them. All of the guys went on to higher education of one sort or another. It was just that the women, the young women didn't do it as frequently as the men at that time.

Attempts at driving

Young: We talked a bit about the independence associated with getting a power chair. How about driving? Did you ever start to drive?

Heumann: A couple times, but I'm not strong enough to drive. I took a driving lesson or two when I was in college or right out of college, but my arms are really weak, so I wasn't able to turn the wheel. I couldn't turn the wheel to steer it and hold my balance. Then when I went to Berkeley, to graduate school, Rehab [Department of Rehabilitation] had sent me to Texas to be evaluated. That was in like 1978 or something.

Young: Was that TIRR [Texas Institute of Rehabilitation and Research] in Texas, in Houston?

Heumann: I believe it was at Baylor, not TIRR. They told me that what I needed hadn't been designed yet and that probably in about ten years what I needed would be designed, which is, in fact, about when it came out. I needed a potentiometer.

Young: What is that?

Heumann: That's like the joystick on a wheelchair.

Young: The hand controls?

Heumann: Exactly, right. Instead of driving with a steering wheel, I would use a joystick.

Young: Is it more the hands or the upper arms that's the issue?

Heumann: Both.

Young: Okay.

Heumann: So, now they've got the technology, but these vehicles are about $50,000. So they're outrageously expensive. They'll train one other person to drive the vehicle. They're very technical. Quite frankly, I don't know if I have the physical stamina to drive. They design the car for you, and once the car is designed for you, it's your car. So, at this point, no.

— 53 —

Young: If something goes wrong, you can't exactly sell it.

Heumann: Exactly. My husband drives, so the truth is, right now, he does the driving.

Young: How was that over the years? I mean, through college, and graduate school, and Berkeley?

Heumann: Not driving?

Young: Yes.

Heumann: That was just another thing I couldn't do. I mean, it's a problem to the extent that I can't get in and out of people's cars. I mean, it's another that you can't do what a lot of people do. In Berkeley, it wasn't *as* bad, because I had a lot of friends who had vans. Before I knew my husband, well, I had a van since 1979, so either my roommates or my friends would drive the van, and then I had friends who had vans.

Young: Oh, so you had your own van with a lift?

Heumann: Oh, yes. I just didn't drive it.

Young: Oh, okay.

Heumann: I mean, it's not the same as being able to get into your own car and driving.

Young: But it enables you to get around.

Heumann: Oh, for sure, yes. I've always lived in cities, so the problem was really, you know, when I was growing up there was no BART [Bay Area Rapid Transit], no metro, no trains that were accessible, the buses weren't accessible. But now, at least in the urban areas, there's a lot more accessible transportation, plus the fact that I have a van.

Young: You mentioned that in high school you weren't able to participate in a lot of the extracurricular activities because of the bussing situation to go home after school. How about working? Did you work during high school, during the summers? How did you spend your summers?

Jobs while attending school

Heumann: In summers I went to camp. I didn't work in high school.

Young: We talked about that for like three or six or eight weeks, so what about the rest of the time?

Heumann: I was in camp most of the summer, and when I wasn't in camp I was at home.

Young: Oh, so you could do multiple sessions of those three or six weeks?

Heumann: Yes. When I was in high school I went to Camp Jened, and that was for four weeks. I think one summer I went for eight weeks, one summer I went for four weeks, and then I went to a day camp kind of a program that I went to for a bunch of weeks. I was always busy in the summer. My girlfriends didn't work.

Young: Oh, really? Okay. Maybe I'm projecting back a perspective of my high school days.

Heumann: Yes, no. My brothers worked when they weren't in camp. They worked for my father. I think they were in college then when they worked for other family members.

I worked in college every summer, and I worked in college. When I was in college I worked also some years. I did work study and one year I worked in the president's office, one year I worked for the disabled students program, two summers I worked at a senior center as a social worker—you know, like a summer social worker intern for two summers—one summer I worked at the camp, and I don't remember what I did the fourth summer.

Young: We'll talk about college more fully in a moment. Anything else about high school that you think is important to add?

Difficult transitions from segregated to integrated classrooms

Heumann: I've talked to people about these transitions, that it was difficult for me to transition from a segregated school environment into an integrated school environment. I think that there are these assumptions that you can just move people from one environment to another without talking about it, without looking at what's going on, and I think that's a mistake. There are differences between segregated and integrated environments, and while the integrated environment is a better environment—when people have been separated—there are messages that are being given, that were given to me as a disabled person.

Who was I talking to today? I was talking to somebody on the phone today. Who was I talking to? Oh, a parent. They were talking about how these kids were being included in school, but during lunch period and social times, the nondisabled kids didn't socialize with them. So they had somebody who was working on helping the two get together—the disabled and nondisabled people get together.

Well, you know, that was something that went on in those days also. Only, there wasn't anybody there to bring people together, and I always felt it. I mean, I had some nondisabled friends in school, but, as a rule, I didn't feel like I really belonged there, because in a certain way, I didn't. I didn't belong in the segregated environment. You know, it's not to say that if you don't belong one place, you do belong to some place else, at all. But I certainly didn't belong in the segregated environment. But I think going from very small classes to large classes—everyone had difficulty moving from elementary school and middle school to high school—those are traumatic transitions for anyone.

Health professionals and socialization needs

Heumann: But I also think not having a motorized wheelchair was a really big problem. I think if I would have had a motorized wheelchair it would have made a really big difference, because I still wouldn't have been able to do things like go to the bathroom by myself, but I would have been able to get around in the hallways by myself, and I think that would have just made 100 percent difference.

Young: It lets you be a lot more assertive, in control.

Heumann: In charge of myself, right. But that was the other thing, that, you know, health professionals and social workers and others never looked at. You needed to be able to walk because of whatever walking is supposed to bring you. They didn't look at what happened if you couldn't walk and you couldn't also independently get around.

There wasn't any real thinking about what facilitates good socialization and what doesn't, and I think that's something that I try to talk to parents about a lot. It's, you know, look at what are age-appropriate activities and help kids, however they do it, to be able to participate in age-appropriate activities as independently as possible. But, at the very least, to be in charge.

So it's not like independence at the cost of, because you go to these situations where it takes somebody so long to do something independently, that that's no longer appropriate, either. You know, if it takes you five minutes to do something that it takes somebody else four minutes to do, well, that's not a big deal. Maybe. Unless you're exerting a lot more energy than that person. But if it takes you thirty minutes to do something that it takes somebody five minutes to do, that's a very big deal. You can make the choice, ultimately, to do it, but—

Young: Independence can be its own form of dependence.

Heumann: Exactly. Yes, absolutely.

High school graduation fiasco

Heumann: I think for me, graduating high school just kind of allowed what I was feeling to be graphically displayed. We were graduating at Brooklyn College, which, of course, had a stage that wasn't accessible.

Young: Did they always have it at Brooklyn College?

Heumann: I don't know. That year they were held at Brooklyn College. I don't think they were usually held at the high school because their classes were too big. I don't know. Sixteen hundred kids in my class—a large class. Maybe it wasn't that large, but it was a large class. However many kids there were, we graduated at Brooklyn College.

I was getting an award, and everyone who was getting an award sat on stage. We had rehearsed it at the high school, and when we got to the college, my father went to take me up on stage—tipped my wheelchair back and pulled my chair up so that I—not to stand on stage, but to get me on stage—and the principal came over and said I couldn't stand on stage.

Young: Because?

Heumann: Because he didn't want me to be carried up the steps. I was mortified, and I wanted to leave. I was so furious that I started to cry. First of all, I was so completely surprised by it. I mean, on the one hand I was completely surprised by it, and the other thing, I think it was waiting for something to go on for four years. You know, you feel uncomfortable the whole time that you're here, and on graduation day they tell you, "You're absolutely right. You should have been feeling uncomfortable for four years. We don't want your butt around here." You know?

So I told my father that I wanted to go home. My father said, "Forget it." I guess we had this thing with the principal, so the principal let me sit on stage.

Young: This is the day of graduation?

Heumann: This is the night of graduation.

Young: Right.

Heumann: This is like people coming into the whole auditorium.

Young: It's not like a dress rehearsal.

Heumann: No, we did the dress rehearsal at the high school, and there was no problem. So the principal made me sit in the back of the stage, last row, and wouldn't let me come to the front when the award was given.

Young: Because he didn't want people to see you in a wheelchair? What was the deal?

Heumann: How do I know? Believe me, I didn't interview the guy afterwards, you know? That was it. I graduated high school, finished. But that was my last day in high school.

Young: That kind of captures it.

Heumann: Yes. It really did.

Empowerment gained by motorized wheelchair

Young: I don't suspect you identify much with your high school friends.

Heumann: You know, there are things I enjoyed about high school, but I actually don't really have any friends from high school. Even the people I knew who were disabled. I know one person from the high school who I actually went to college with, and that's the reason why I still know her. But I don't have a single friend from high school. That's a pretty strong statement. Because I have friends from elementary school and friends from college.

Young: What were some of the best highlights of high school? I mean, it's pretty clear that there were some pretty bad experiences.

Heumann: Oh, I was in this honors English class. I liked it because it was a smaller class. There was more discussion. I liked my history classes. I was in Sing for two years; that was okay.

Young: That was the name of a choir?

Heumann: Oh, the freshman class, sophomore class, junior class, and senior class did a production every year. It was called the Sing. But I knew that I would never get cast in any role—it was very clear—because I was in a wheelchair.

I think, really, the fact that I didn't feel empowered—I mean, I felt empowered at certain times—but having to be pushed or pushing myself very slowly and awkwardly always made me feel different. Now, I don't go any place, as a rule, I mean, I never travel if I can't take my motorized chair. Any place I go, I take my motorized chair. I don't care where it is, I take it. I take my manual chair if I go to another country, and I'm going some place where there are a lot of steps, I get out of my motorized wheelchair and go into the manual chair, but I'll never leave my motorized chair at home.

Young: A lot hangs on the chair. That's a pretty powerful statement about the importance of technology.

Heumann: Oh, yes. Yes, the chair's the most important thing for me. Yes. It's kind of my personality, you know?

Young: How does it shape your personality?

Heumann: Because I'm a very active person, and I move a lot. I feel a lot of times like I'm still making up for the first twenty-one years of my life where I couldn't easily move around.

People who speak on the phone, some of them stand in one place. They'll stand on their left foot, they'll stand on their right foot, they'll go back and forth or lean against a wall. Some of them will sit down on the floor. Some people will sit on a chair. Some people will pace. I'm a total pacer. [laughter] I'm back and forth. My husband will come over sometimes and shut the chair off and say, "Stop moving. You're making me crazy!" [laughter] I won't even know that I've been moving. But I like the feeling of movement. In my office and every place, I like to be doing, so the motorized chair lets me do a lot of stuff.

Young: That makes a ton of sense to me. I'm smiling because I told you that I just started to use a chair. I'm always the kind of person who, if I'm standing, is looking for a place to sit or a place to lean. But, in the chair [laughter] you know, I was down in Denver, and I found myself just moving, just little turns.

Heumann: Exactly.

Young: Just to be in motion. There's something really neat about that, as opposed to feeling like you always either want to or need to be still, to have that freedom to move is really liberating.

Crutches and braces for therapeutic exercise versus walking

Heumann: Well, I used to use crutches and braces. I mean, I used them until I was twenty-one. But I never was independent, and I was always afraid of falling.

Young: There's a huge stamina issue, I would think, too.

Heumann: Well, I mean, the stamina was different because my arms are not strong, so I used to have crutches that went under my arms and braces that came up to my chest, and my knees were locked and my hips were locked. So I would basically be able to do little steps, but it would take me about half an hour. It would take me a long time. I couldn't walk up steps, I couldn't walk down steps. I mean, I couldn't walk up inclines, really. I couldn't break my fall. So it was not really an issue of my getting really tired, it was just that it took me so very long. I never could walk across the street by myself unless there were no cars coming for five minutes, ten minutes. I would never get across the street. A big street would take me thirty minutes to get across the street. It was very impractical.

I think I've said this before, but I think it's so unfortunate that there wasn't an effective mix of standing and walking for legitimate reasons, not walking for a functional purpose, but for weight bearing and for exercising. So when I finally had the opportunity not to wear my braces anymore—I don't know, did I tell you this—then I had my spinal fusion.

Young: You told me about the issue of weight bearing, that that presents a problem.

Heumann: After I had my spinal fusion, when I went back to get braces, the doctor prescribed the wrong braces. Did I tell you this?

Young: You referred to it.

Heumann: They prescribed braces that were only to my waist. So when they went to order the braces, I said, "Those braces aren't going to work." They said, "That's what the doctor ordered." I said, "They did a spinal fusion. They didn't do a trunk fusion, and I don't have any stomach muscles. So it doesn't make any sense to me that they're giving me a brace to my hip."

Young: Was it a new doctor that you hadn't seen?

Heumann: It was the doctor who did my spinal fusion.

Young: So he had no experience?

Heumann: But he wasn't my doctor before. Exactly. I thought, "Well, I've done my best. I've been as honest as I could about what I need, and I know when they give me these braces that they're not going to work." But, you know, my parents really wanted me to have those braces. So we got the braces. I think I wore them three times.

Young: They just didn't work?

Heumann: I couldn't walk. I couldn't even stand, because, while they'd fused my back, I had no upper trunk muscles. I had to have something to hold me up straight, you know. So I put the braces and the crutches in the closet and I never walked again. That was that.

Young: How do you feel about that?

Heumann: Well, I do wish that I had braces today.

Young: Is that still an option?

Heumann: Well, sure. I mean, I could go back and try to get a set of braces, but it's kind of ridiculously impractical. Again, it wouldn't be for the purpose of walking, it would be for the purpose of standing and bearing weight and just getting your organs in place.

Young: That's not possible without the braces and—with a walker or other types of things?

Heumann: No, I can't stand at all. A walker is nothing for me. I was never good with a walker. They have got these standing tables and stuff, but I haven't borne weight for so long that I don't even know what I would have to do to start doing that.

Young: They're actually doing some pretty wild things with chairs these days. I don't know if you've seen these golfing chairs where it's a motorized chair, and you're sitting and you move along, but when you want—

Heumann: You can stand up.

Young: —it will raise you up and stand you up.

Heumann: Yes, right.

Young: So you can swing your golf ball and then get back down.

Heumann: Right. Those are the people who can bear weight. I mean, I don't have the time, but it is something that I'd like to do. Because first I'd have to see whether or not bearing weight would be a problem at this point. But I like standing. I've never felt badly about standing. But it was just this extreme—you have to do this. This is the way to do it. You have to be able to walk. Very ridiculous.

Young: Did you feel much different when you were standing?

Heumann: Versus being in a motorized chair?

Young: Or a manual chair.

Heumann: Well, sometimes I would feel very stuck because I couldn't walk quickly by myself. Or sometimes it would just feel good. In many ways, it depended on the situation.

Young: How about the identity level, in terms of—

Heumann: Standing—

Young: Did you feel like a different person?

Heumann: From an identity perspective? No, I didn't feel like a different person, because, again, you know, I couldn't walk well by myself. I couldn't pass standing, you know? You saw my braces, you saw my crutches. I couldn't just pick up and go walk down the street with you. So, actually, being in the wheelchair was more independent, because even if I couldn't push myself, somebody could push me. So the wheelchair was always more practical.

Young: Pushing you while you were standing wasn't too practical. [laughter]

To be or not be disabled

Heumann: That's right. Although, when I was younger, my friends knew how to walk with me with my braces.

Young: On the NPR [National Public Radio] program on Monday—this is getting a little off-subject—I heard a caller refer to how you had said that if you were able to have some miracle pill that would enable you to walk—

Heumann: To be nondisabled.

Young: To be nondisabled—that you wouldn't do so. That's kind of a part of the identity issue that I'm thinking of, because part of what you were saying about the chair, and from my own experience, it goes far beyond a functional thing. I mean, it becomes a part of who you are. Will you say a little bit more about your feelings about that?

Heumann: People think that what disabled people want to be is nondisabled, or what I want to be is nondisabled, and the truth of the matter is that if somebody came up to me today and said, "I absolutely have something that unequivocally would enable you to walk, would you take it?" I don't know what I'd say.

But I don't ever say that out loud to people, because the message there would be the wrong message. The message is, "I don't want to be you." You know, "you" meaning a nondisabled person. But do I want to be able to have a life which is not hampered by my disability? You know, I definitely believe that it's the social environment, et cetera, et cetera, but if somebody came to me and said tomorrow, "I definitely can give you this so you can go out and drive. You don't need an attendant anymore. You don't need to do all these things. You can go buy a house and you don't need to worry about whether you're living near a metro, because you can drive," and all that stuff. That's, of course, what I thought on Monday when this guy said this to me, but I wasn't going to say that.

It's totally the wrong message to say to people, because the truth is it is very possible to create a society where being in a wheelchair and needing the level of help that I need is practical and feasible, but it's the system around that makes it so difficult. So, when you get to be fifty years old and you've been doing this as long as I've been doing it, I really thought, "Well—"

Viewpoint on Christopher Reeve

Heumann: I mean, the Christopher Reeve thing—you know, I feel badly for the guy. I don't say that publicly either.

Young: Why would you feel badly for him?

Heumann: The guy is very, very seriously disabled. He is a C1 quad. He's like living on a broken rubber band. I mean, that little bit that's left could pop at any minute. He was a completely independent guy who did everything by himself.

Young: Superman!

Heumann: Right. Well, he was a person. He wasn't Superman. He was just an average person. Now he can do very little for himself. What I feel badly about for him is that I don't believe a trillion billion dollars that guy is ever going to walk again. His wife knows that. Did you see that piece about him last week on Friday with Barbara Walters?

Young: Yes.

Heumann: First of all, I think the good things that he's doing—

[Tape 5, Side A]

Heumann: —and so many relationships break up when someone acquires that level of injury, and who knows what would have happened if they didn't have the money they had. But they seem to be a pretty strong couple. She seems to be pretty grounded. She's not talking about him walking. She's talking about him getting one arm and getting off a respirator, which, in and of itself, is probably not going to happen, but it's a lot more in the realm of practical and feasible than getting him up in those things and getting him moving. Except for that, I also think the guy, on a very real other level, has gone on with his life.

Young: He's now directing. It's phenomenal.

Heumann: Yes, it's great. I'm not in the camp of being critical of who he is. I mean, I understand very much that we don't want the message out there that my life is a tragedy if I can't walk.

Young: And that society has no responsibility but to cure the people so we don't have to deal with them.

Heumann: Exactly. I don't think he's exactly saying that either. I think he's saying, "My life's pretty tough right now, and if I could walk, my life wouldn't be like this anymore." That's not a lie, you know? What can you say? The guy probably has more people helping him than he needs to have helping him because he's got the money that he's got, but the reality is that he needs a lot of help, and it's pretty expensive. If he wasn't who he is, he probably would be dead. You know, so there are all those real things that go on all the time.

Young: I wonder how many C1 quads there are.

Heumann: Oh, there are others. Definitely there are others out there.

Young: I was just thinking about what you said, that it would take a lot of dollars to sustain that.

Heumann: Yes, but he's certainly living a decent life. I mean, he had enough money to renovate his house. He lives in a beautiful house in a beautiful place. But I do think that the other message there is that he is directing, he is out there, he is flying, he is getting around. He is showing people that here you have somebody who has got a very significant disability who really is breaking a lot of fantasies about what people can do.

So I don't think any of this is in a neat package. We'd like everything to be neatly packaged. I don't think there is any such thing as a neat package.

He could be out there just raising money for the cure and not doing anything. That would be a terrible message, but, you know, he's basically, "Well, I'm waiting for the cure, but while I'm waiting, I'm getting on with my life." So I think in the next couple years he's going to have to make a decision that the cure isn't going to happen, and his life is going to be different, and he's going to continue to go out there and direct and maybe have another kid.

That I didn't like. That is something that I didn't like on the program last Friday where he said he didn't want to have another kid because he couldn't do the things for his kid. That bothered me. That bothered me more than the curing.

Young: Why did that strike such a strong chord?

Heumann: Because, on the one hand, well, this is great that he's a man and he wants to take these kinds of responsibilities and he feels like he's physically not going to be able to do it so he doesn't want that to happen. On the other hand, he has many people working for him who can pick the kid up and put the kid on his lap, and he can take his share of responsibility. His wife can go out. He can use the attendants that he's got to direct them on what to do that he can't physically do himself. So, that did bother me more than this thing on wanting to be cured. But, I don't know.

Society versus the individual

Young: I want to follow up a little bit on this issue of society versus the individual. You talked about how you could imagine a society where being in a wheelchair isn't a problem, that it's not the disability that's hampering you, it's the society. Have your ideas about that changed over time? At what point did you come to that kind of perspective?

Heumann: I always felt that.

Young: All the way back into high school and college.

Heumann: To me, all this has been very logical. The types of things that I need—ramps—they're not really high, high tech—a good motorized wheelchair that can be repaired, good seating system, and the availability to have people around me to help me do the things that I need to do that I can't do by myself, an accessible house, a roll-in shower, things that I still don't have. But it's not because they're not obtainable. I mean, as long as I can remember, I think, or as long as I've been thinking about it, these are artificial, human-made barriers that don't get removed because we don't have, yet, the political muscle to allow people to understand, one, that this would be good for us, and, two, it would be good for them as nondisabled people.

I don't know if it will ever change in our lifetime, even in your lifetime, which will be longer than my lifetime. I wonder at what point nondisabled people are going to say, "Okay, I'm seventy-five years old, but I still want to be able to live in my own home. I'm going to need assistance, but I want to be able to get it in my home. I want an environment that I'm living in which I can use. I don't want to go off to a nursing home." Or, "I don't want to go off to a senior living community," you know, "where I don't know anybody, and there's no reason for me to have to be able to do that."

Young: We'll come back to that on a couple of occasions.

Heumann: Okay.

Disability overshadows all aspects of personal life

Young: A couple of final things before we head on to college. I feel like we'll actually get into the twenties.

You think about issues, parts of identity formation, race, class, gender, ethnicity, age—where do you see disability fitting into these other categories? Is it kind of one of equal footing among all of those, or does disability stand forward?

Heumann: Do you mean for me personally in my life?

Young: Yes.

Heumann: Oh, I thought you were going to ask me how it fits into each one of those categories from other people's perspectives.

In my life, disability kind of overshadows almost everything almost all the time.

Young: But?

Heumann: Not all the time.

Young: It sounded like a "but" was coming.

Heumann: No, not all the time, *almost* all the time. You never really forget that you have a disability. Well, people would say to me, "Oh, I didn't even remember you were in a wheelchair." That's like the biggest crock. [laughs] Because, since *I* can't forget that I'm in a wheelchair, how can they forget I'm in a wheelchair? I mean, I can't forget that I'm in a wheelchair because there isn't a complete day that can go by where I can, from the time I wake up till the time I go to bed at night, do everything in a free and easy way. Because if I want to be able to have the world as my opportunity, to be able to go out and about and do whatever I want, I can't just pick up and say, "Oh, let's just open the map and go there." I have to think, "Okay, where is there? Is it accessible? Is the bathroom accessible? Do I need somebody to come with me?"

Also, I think, the other reality is that this job has been helpful on a certain level, because I have spent the most time I ever have in my entire life with nondisabled people—outside of before I was five years old—or nine years old when I went to special ed classes, I guess, before I was nine. But, no, then there was high school, which was a very uncomfortable period. I guess I could relate the beginning of this job to the feelings that I had when I was in high school [laughs] because I knew I needed to be there, it was uncomfortable being there, and I knew that I had to complete it. When I first was in this job, I felt uncomfortable, and I knew the people working with me felt uncomfortable.

Young: Because they were all career people who—

Heumann: No, they weren't all career people. The people that I spent more time with in the beginning were *not* career, actually, they were political, but they were all nondisabled. So it's like you could just tell.

Need for accessibility features at RSA

Heumann: When I first came into this job, the disability stuff was there immediately—bathrooms not being accessible and my saying they had to be. Some of the things that went on. But when I first came here, the bathroom in the building that I was in was very narrow, and the only way that I could go to the bathroom was my attendant had to literally put one foot on the toilet, because it was so narrow. So they were going to make one of the bathrooms accessible for me; they weren't going to make the men's bathroom accessible, because I didn't need the men's bathroom. I said, "Forget it. We have to make the bathrooms accessible."

Then I was told that the bathroom that was "accessible," met GSA [General Services Administration] standards for the time that the building had been built. I said that I didn't care if it met GSA standards, it didn't meet today's standards. So I remember making a phone call to the Architectural Barriers Board [Architecture and Transportation Barriers Compliance Board], and asking them if they would send somebody over to look at these bathrooms, and GSA calling up, being furious that I had invited another agency to come in and look at this.

I got called in by the deputy chief of staff who was upset.

Young: From the White House?

Heumann: No, in the Department of Ed. I should have kept a diary. I know I'll rue the day I didn't. But I wound up having a conversation with this person. She was African American. Today she is the chief of staff. She basically had this discussion with me which clearly indicated that she not only knew nothing about disability, but she <u>really</u> knew nothing about disability, and she was asking me some of the most inane questions, like how did I move this, how did I move that. I just remember sitting there and going, "Okay, you have to listen to this, and you have to respond to it, but I can't believe I'm doing this." It was just so wacko.

But I learned in the very beginning of the job that you just hold your ground, and I held my ground, and eventually the point was made that this building that we were in not only had to have a bathroom for me that had to meet current standards, but there had to be one for men and one for women, and there had to be one on every floor. <u>And</u> there had to be an electric door at each one of those bathrooms so that people could get in and out. So that eventually happened.

Young: How long did it take?

Heumann: Not too long. It was probably within six months to a year that that happened.

Young: That's not bad.

Heumann: They had carpeting in my office that had just been laid down before the previous director left.

Young: Nice fluffy carpet?

Heumann: It wasn't fluffy, but it didn't meet code, and it was hard for anybody in a wheelchair to get over it, so I told them to rip it out. They told me it was new. I said I didn't care. Get it out. So they got it out.

Relationship with Assistant Secretaries, U.S. Department of Education

Heumann: So I began to learn, "You are the assistant secretary, you have authority over here. Use it." So that's the way some of the changes have been made over there. But what continued to go on was that I felt people were—people had made friends at this level—you know, the assistant secretaries, and I feel friendly with all of the people.

Young: Wait. You lost me a bit. People make friends?

Heumann: The assistant secretaries.

Young: Oh, the assistant secretaries make friends together.

Heumann: Yes. Well, we're not all social buddies, but there are social relationships, I think, that have developed.

Young: I didn't know if you were talking about other people outside.

Heumann: No, in the department. No. These things that are going on are not just disability/ nondisability, but also male/female, because some of the men have known each other for longer periods of time. I didn't know anybody when I came into this job. I didn't know any of the political people. Some of the other political people didn't either. I think some of the political people don't socialize with the other political people, but we're all friendly towards each other, and some of them do socialize.

Prejudice and lack of trust

Heumann: Then I had another experience in this job. Once a month, the department holds satellite town hall meetings where we have the secretary, and there's a topic, and there's an audience, and they do downlinks from 150, 200, 300 downlinks around the country. The chamber of commerce donates their space.

Young: I didn't go to the first one. I might not have gone to the first one or two. Then I went. I thought, "I've really got to go." So I went to one, to be in the audience. When I got there, there was a flight of stairs. The entrance that I had to go into was on the side through the garbage entrance. So I was furious. I was so pissed.

Nobody had checked that out, evidently.

Heumann: So that Monday morning at our senior staff meeting I raised the issue. I said, "We need to move this. We can't do this. It's not appropriate. It's not appropriate for me to have to go through a garbage entrance. It's not appropriate for any other disabled person to have to go through a garbage entrance."

I was told that this was free space and we weren't going to be able to move it and that they would deal with it. So they got this very big ramp, and every Tuesday I'm sure, still—I haven't been there in ages—I was there in January. No, we did one in January. They moved it to some place else for this particular show.

But, at any rate, this was still a couple years ago, it was the first year I was there—1993. There was an article in the newspaper. Some disabled people—I don't know who they

were—picketed the chamber of commerce for lack of access. There was a picture and a heading underneath it. I remember either seeing it or somebody telling me about it and then looking at it. Then, that same week, the chief of staff asks me to come in to talk with him, and he shows me this picture. He says to me, "I don't believe in coincidences." I thought, "What is he saying?"

Young: He thought you set it up?

Heumann: I mean, it was like one of these, "I want to have a party at my house, and I don't want you to come" kind of things, that I'm trying to fix it. It was the exact same kind of a feeling.

I'm, like, "What?"

"I don't believe in coincidences."

I said, "You think I did this?" I said, "I don't even know who these people are." Which is the god's honest truth. I have no idea who these people were.

It was this issue of was I a team player. In point of fact, I knew that with this job, and I know that with this job there are certain things that I want to accomplish, and if I'm not trusted by the people that I have to work with, I'm not going to be able to accomplish it. I'm not going to compromise my principles on what I want to have accomplished, so I will learn how to play their game. If it means not saying what I think about somebody not inviting me to tell me they're having a party in their inaccessible house, okay.

But I remember saying to this guy—we had a whole discussion around it—and I said in the end, "Well, I hope you believe in coincidences."

But I remember those three. Those are at least three of the incidences that were so stark and, to me, really speak of prejudice and lack of trust. They were also in the beginning, in the first year, I think. Things slowly have gotten better as people have gotten to know me more and to trust me more.

Disability agenda misunderstood

Heumann: But the people who came into the administration all were people who had an agenda. They were advocates of one sort or another. Certainly in the department, I was brought in for my qualifications. I was also brought in because I was a disabled person with the qualifications. You know, there were a number of African Americans and Latin Americans. The secretary was very conscious because the president said he wanted a diverse work force, which was great. But I felt—and I've talked to people like Bob Williams, who have said the same thing—that all of these people, within their own constituency, would be considered to be an advocate. But when the word "advocate" was used for me and the word "advocate" was used for Bob, it was used in a way that meant that you were a different type of advocate, and one that didn't necessarily belong to the same team. So you had five advocates in a cluster and an advocate over here.

Young: Because you're not a part of the system?

Heumann: Because I—no—I wasn't a part of their group. I wasn't trusted. They didn't know me. They saw us disabled people as having a different agenda. We played to a different drummer. I think the analogy would be Kennedy running for president in 1960 and being controlled by the Pope. They couldn't say we were controlled by a pope, right? But, because they didn't get our agenda, more importantly, they didn't agree with our agenda. I think they basically agreed with the agenda of the other minorities within the group, but they didn't understand our agenda, and what they understood they didn't necessarily agree with.

Young: So gender and race and class issues are kind of all sort of equally respected but somehow disability—

Heumann: Class wasn't an issue because there were no poor people in this group. Class was not an issue.

Young: So race and gender at least.

Heumann: Well, race and gender—

Young: Disability was kind of on the outside.

Heumann: They were all middle- and upper-middle-class people or more. So, while people had different racial backgrounds, race wasn't an issue because they weren't poor blacks or poor Latinos. One of the guys in the group was an African American guy who actually had been poor when he was younger and actually had had all kinds of problems until he kind of got it together. He's not there anymore, although he reaches out and does some very good work.

I don't have disparaging feelings about the people, but it was very clear in the beginning, this level of discomfort and distrust.

Nondisabled people's discomfort

Heumann: It reminded me of when I worked on a campaign in California—and friends of mine—you know, we clearly felt like we weren't wanted. Or, they were glad that we were there, but they didn't really know how to be with us. It was like a basic not knowing how to be. You know, it's not like you can just be. So the campaign was finished—

Young: Whose campaign was this?

Heumann: I don't even remember. Just some campaign. Whoever's campaign it was, we had won. So we had gone to somebody's backyard for a party. We were standing—I was sitting, and everybody else was standing in a little group—and people started talking about going to the movies that night and nobody asked me to go. It was like, "Oh, would you like to go to a movie tonight? Would you like to go to a movie tonight? Oh, what kind of movie would you like to go to?" I was, like, there. It goes here and here and here, and I just sat

there thinking, "How totally bizarre that these people have now set up—" They were all talking about how great it was that we had won the election and blah, blah, blah, and now they were moving on to the next activity.

I actually went home and called Kitty Cone up. I said, "Kitty, am I a Martian?" [laughter]

[phone interruption]

Heumann: But, no, this feeling of being a Martian. One of the things that I started to do in this job is I have accepted the fact that people are uncomfortable with me sometimes, and I have begun to make fun of people about it in a very New York, sarcastic, sardonic way.

So, one day, we were at another one of these senior staff meetings. Every Monday morning is a senior staff meeting. So every Monday morning I'm the only disabled person sitting around the main table. Sometimes there will be another disabled person in the room who's on my staff, one of my politicals. Now, actually, there's a disabled person who's working in another office, and he comes to these meetings sometimes, so he's the only other person in a wheelchair in the secretary's building who is at a higher level, not political, though.

So, the discussion was about education. People were talking about things that they were doing. This one guy who clearly is uncomfortable around me made some kind of a comment about, "If this happens, we'll be cut off at the knees."

I said out loud, "Oh, and then you'll send them over to us for services." [laughter]

Well, the room was like [gasps].

Young: A little bit too dark of humor.

Heumann: The deputy secretary, who also was not comfortable with me, said, "I'm really sorry. I'm really sorry. He didn't mean it."

I was laughing. I leaned over, this guy was sitting next to me who was another assistant secretary, a Hispanic Latino guy, and said, "You know, I was only joking." So I said, "You guys, it's a joke. It's a joke. Just relax. I'm only joking with you."

I don't think that anybody would remember that, but I think it was kind of important. When I keep feeling this, that they don't exactly know what to do, and they still are playing cutesy about my wheelchair and the speed of my wheelchair. I hate when people say to me, when you're with another person in a wheelchair, "Are you having a race?" I hate that. That will even happen in the building.

Young: Patronizing.

Heumann: Yes. Well, you know, it's people's way of saying something friendly. Because, you know, they're really retarded—I mean [laughs] in the real sense of what the word should mean—they just don't know how to do the basics, and it just really does surprise me, still. I mean, doing a study on this, I think there would be some sociological value in it.

— 70 —

But I think, for me—however we got into this discussion—for me, this job has really taught me different things, because I had to stay in it. It was important for me to be able to do my job, and in order for me to do my job, I'm a very strong networker. I have to be able to work with people outside of my office. So I had to be able to get people to begin to trust me without compromising. Just trying to find that balance. It just takes time. I mean, everybody that I was working with at that level, they're all in their forties and fifties. I mean, these are people who were civil rights leaders, activists, union leaders. So the problem is pretty overwhelming.

Language issues and disability

Young: We are a little far afield from college, but you've mentioned a whole bunch of themes.

Heumann: No, but it's all relevant. I can get back to college.

Young: I want to touch on some of these themes now, but I'm going to come back to them later, so don't accuse me of saying, "You've already done this."

Heumann: I won't.

Young: Because they are big themes that we come to on other occasions.

I'll ask the most recent one you touched on, this issue of language, the joke of being cut off at the knees, all sorts of idiomatic expressions. You know, saying to a blind person, "I'll see you later." Or, one that always bugs me, you hear the traffic reports and there is a "disabled" vehicle.

Heumann: I hate that.

Young: The implication is that it is utterly incapacitated and an obstruction.

Heumann: And the people—

Young: People always use the expression, "This is going to paralyze" this or that, or you talked earlier about how somebody said something to the effect of "I didn't even notice your wheelchair." You'll hear oftentimes—I've heard it oftentimes—"Well, I've never thought of you as disabled." What do you think about some of these language issues associated with disability?

Heumann: I think I separate the "I didn't think of you as disabled" from the use of the words of "disabled car" and things like that. I think that they may be similar, but I think of them differently.

I think, "I don't think of you as being disabled," or, "I don't remember your wheelchair," I don't know if it's not really being genuine, or maybe what they're saying when they say to me, "I didn't see your wheelchair," is that they really did finally get to know who I was, and I'm not my wheelchair. But, on the other hand, the wheelchair is part of me. So, sometimes my fantasy is that when I'm dealing with people, if I could draw it, I would draw it like this. Here is the page, and here would be the wheelchair, and here would be me. When they're first dealing with me, all they see is the wheelchair, and so there's this little voice that they probably can't even really listen to, because they're overwhelmed by the wheelchair.

Young: They're looking around and all distracted.

Heumann: So maybe over time I get to be like this, and maybe it's when I get to be like this that they're seeing me sitting in the wheelchair, and that is a different image. But if they can't combine the two, because it is a part of me—it isn't me, but it is a part of me—to me, what it means is that people don't understand a number of things. One is they are likely not to think about inviting me to go some place that's not accessible.

Dinner at pre-Beijing conference

Heumann: It's like when I was at the pre-Beijing conference for the U.N. meeting on women, and we had all been working late at night, and women were going out to dinner. A group of women went out first and called us to tell us where to join them. This was like another perfect example. I was just being me, I was doing my work, I was having a really good time, dah, dah, dah, dah, dah, and a bunch of us go walk down the street. There were curb cuts, I knew I could get across the street, and, there, we get to the restaurant, and there was a step.

So everybody looks at me, we look at the step, and nobody says, "Oh, let's find another place." It was very clear that everybody wanted to go into that restaurant, and that it was for me to say either, "Lift me up," which you can't do with this wheelchair because of the tip bars on the back, and which I didn't really want to do anyway, or for me to say, "Oh, I have a meeting," which I did have, "and it's no big deal. I'll just go back and eat in the hotel."

The truth of the matter is, I would have liked those people to say, "Let's go find another place to eat," and not for me to have to say either, "I'm going to go to the hotel," or I could have said, "Let's all go out some place to eat." But the truth was I didn't really know these women. It just became this group of women leaders. Here were all these women, and I was kind of over here, but, a week ago, I would have felt like I was over here. So I was feeling a little bit like a part of the group, but I very quickly went back over here.

Young: You could even have said, "I will go back and have something to eat at the hotel," if they had at least shown the respect to say, "Let's move."

Heumann: Oh, yes, I wouldn't have, because the truth of the matter is I was going to dinner with them. I had a meeting, but the meeting was an hour later. I had planned it because we had agreed we were all going to dinner. So it was completely disingenuine on my part to say it's not a problem, because it was. I find it amazing.

Young: So what did you do?

Heumann: I went back to the hotel, and I had dinner at the hotel, and I had my meeting an hour later. But I didn't stay at the same hotel as the women in Beijing because the hotel they went to wasn't accessible for somebody in a wheelchair. They had a separate bus that wasn't accessible, so I was in a separate vehicle. You know, it's like the message was very clear.

"I didn't see your wheelchair"

Heumann: But, on the other hand, I had an agenda, and my agenda was to integrate disability into their agenda. But, you know, they were continually uncomfortable, they saw my wheelchair.

But when you don't see my wheelchair, when you tell me you don't see my wheelchair, I have no level of confidence that you know who I am. You don't understand the political issues, you don't understand the civil rights issues, and you probably don't understand—skipping those things—the most basic issues of access, because you basically can't combine the two. It's like saying to a man, "Oh, I didn't see that you were a man." [laughter] It's illogical, right? I mean, how can you say, "I didn't notice you were a man"? Of course you notice you're a man. You notice your skin color. When racial minorities get the same kind of comment, "I didn't realize you were black," it's like, "Well, if you were blind you wouldn't realize I was black, but if you're not blind, of course you see I'm black." What does it mean to say, "I don't even see your color anymore"? What do people mean by that?

Young: Well, it's sort of a backhanded compliment.

Heumann: They think.

Young: Right. I mean, to use the expression of, "I didn't see you as disabled," it's meant to be a compliment like—

Heumann: You're just like me.

Young: Yes, "You're just kind of one of the guys."

Heumann: Right.

Young: But what it's implying is that disability is this horrible, dreadful thing that you somehow have managed to escape, rather than to see that you can be disabled and be accomplished or active or whatever. They kind of separate that if you're active, that's not part of what disabled means.

Heumann: Exactly. It's striking to me. Right. But it's alive and well. To me, because it is so extreme, the barriers and the problems that we have to overcome are tremendous. I mean, they're just tremendous.

Politically correct language

Young: Now, how about the uses of speech, saying to a blind person, "I'll see you later," or making a reference to breaking a leg.

Heumann: You know, my feeling about that is that if the blind person would say to me, "I don't like for you to say, 'I'll see you later'" I respect that, but outside of that, I don't think about that as an issue. I don't like the word "disabled car" because—

[phone interruption]

Heumann: People say, "You know, we shouldn't use the word 'disabled.' It means you're not able." I have felt that the word disabled is a political term. It's like black or African American or Latino or woman. It's a word that we use. These words do get changed, but it's a word that we have adopted. To take it and use it for an inanimate object when what we—. Remember Easter Seals? Maybe you don't remember, but Easter Seals had put out this set of pamphlets on correct terminology.

Young: No.

Heumann: Oh, get it. You've got to get it. Not that long ago, in the last ten years. They mailed it to all the media, you know, why you shouldn't use "cripple" and dah, dah, dah, dah, dah. In the last few years, all the words have continued to go back into the "crippled car", the "paralyzed car", the "disabled car". No, but actually the word cripple is now being used all the time in relationship to disability.

Young: By people with disabilities?

Heumann: No, in the media. Take the *Washington Post*. Read it. I see "crippled" all the time. There was a while where you didn't see it that often, but I see it at least once a week. You even hear it on TV in newscasts sometimes. So it's our word. Some disabled people say, use the word crippled because that is what people think we are. Put it in their face. "Disabled" is a word that we want to use to describe ourselves, and the media has chosen not to use our terminology and to use it in a completely inappropriate way. I feel like some people would argue that therefore we should change what we call ourselves because the media use it the wrong way or others use it the wrong way, and I feel like it's symbolic of people not listening to us, and I don't want to start going out looking for a euphemism of what we should be calling ourselves.

[added during editing: In the 1970s when the disability movement emerged, we stopped using "handicapped" and began using "disabled." Then nondisabled people got involved and started to influence people-first language. While I understand why some people have discussed not being treated like a human being but rather like an object, I object to changing our language and do not subscribe to people-first language.]

Young: The physically challenged.

Heumann: The able disabled. Whatever the words are, I hate them. I think, you know, Paul Longmore's all broken up about this. [laughs]

Young: He wants a new term.

Heumann: He does want to change the word?

Young: In part for the ableism idea, to have a way to talk about racism, but also a way to talk about, say, body studies or something. This way, when you talk about race, everybody has a race, you know, whether you're white, yellow, or black.

Heumann: Yellow people—don't ever call them yellow.

Young: Gender. Everybody has a gender, male or female. If you use the expression "disability", arguably not everybody has a disability, so it's somewhat exclusive. So he wants a way to talk about the experience of what disability—

Heumann: What do you mean, not everybody has a disability?

Young: Well, there are nondisabled and disabled.

Heumann: Right, but there are blacks and there are nonblacks.

Young: Right, but when you use the word "race", you can apply race to everybody.

Heumann: Sex—

Young: —disability—sex, gender—

Heumann: —religion—

Young: —class, you can apply all of these things to everybody, whereas, if you talk disability, it doesn't apply. You can talk "body." There's all this stuff now about body theory. Everybody has a body, but then that doesn't catch the mental element, so that's not all-inclusive either. I suggested, you know, maybe function, but he thought that gets more negative connotations. I'm not sure it's any worse than disabled. But, so he's kind of searching for a term.

Heumann: He's searching for a term that encompasses everybody?

Young: Well, that's an analytical tool that would be applied.

Invisible people with disabilities

[Tape 5, Side B]

Young: When we talked a bit about how people just don't know how to act, they don't know what to say, they're uncomfortable, it raises a bit of an issue of intentions, that there are people who want to assist people with disabilities or open doors or do things. I'm trying to think of good examples.

Heumann: I don't even necessarily feel that that's where people feel they have to go. I don't feel like the people that I'm talking about feel like they don't want me in their house but they'll open a door for me. I feel more invisible at times than like somebody wants to do a charitable deed.

Young: Yes, I see that, but not so much in the examples that you were saying. You talk about people who don't know what to do. That there are people who are trying to do what they think is the right thing, but are doing things that are kind of half—

Heumann: Maybe they necessarily aren't trying to do the right thing. That incident—she clearly knew she wasn't doing the right thing. I think there was a very strong statement that was going on there:

"I'm <u>not</u> going to do the right thing." They may feel like crying, and they don't know why they're crying about it, but that was, I felt, a pretty intense statement, you know, from a woman who was African American, who deals with discrimination as her job. I will never ask her. I should never say never. But it is unlikely that I will ever sit down and have a discussion with her to ask her from where she was coming.

Identity and discrimination, gender and disability

Young: Let's talk about that a little bit, because these issues of identity and different types of identity, different experiences of discrimination are really fascinating to me.

You knew Peg Nosek down in Houston?

Heumann: Yes.

Young: I had a fascinating discussion with her. She's now running this institute on disabilities, women with disabilities. She made the comment that in working on this issue, that she's come to the realization that all along in her life when she's felt as if there has been disability discrimination and disability's been an issue, that, really, gender is the bigger issue.

Heumann: [sniffs/snorts] Uh huh? Okay.

Young: Well, that's a pretty strong reaction. I just wanted to see what you thought about it. I've <u>never</u> heard anybody say that. I mean, it caught me off guard. How do you weigh the experiences of discrimination—you're shaking your head vehemently—between your experience as a woman versus being a person with a disability?

Heumann: I absolutely know that in this job I am discriminated against because I am a woman. There is no doubt. I could have a very serious discussion about the sexism that exists in the workforce that is perpetrated <u>by</u> women.

I was at a conference that we had a couple of weeks ago, and there was this wonderful African American woman speaker. She was tremendous. She was talking about diversity. She says there are things that we have in common that are unspoken but are there. She looked at this black person—there's a group of like three hundred people there—and she

looks at this black guy, and she said, "I bet that you and I would agree that we had experiences growing up that are in common."

He said, "Absolutely, yes."

They didn't know each other. He wasn't just saying that. She actually knew that there was a common link because of their color.

Then she said, "And now I'll talk to all of you in the audience who are women." She didn't break it up by race. She said, "How many of you have had the experience where you put out an idea and nobody says anything. And a little bit later—"

I was sitting on the dais, and I just interrupted her and said [shouting] "And a little bit later a man has the same idea, and he says it, and everybody says it's brilliant." She starts laughing.

I had just had this conversation with some friends of mine like a couple of days ago. [laughter] I've had the conversation a number of times since I've been in this job, because it is so striking. I mean, I can be in a room—I'm the boss, right—I have people under me who are not at my level. I'm not into this elitist hierarchical thing, but I sit there. For the first year or so that I was there, I was just dumbfounded. You know, "Is this because I'm disabled? Is this because I'm a woman? Is this because I'm a disabled woman? But I'll put out an idea and thirty minutes later I'll direct somebody: [pounding with each word] "Go-do-this!" They will go implement it, and it will be their idea. I'm like, "This is bizarre."

But, you know, when I heard this nondisabled black woman say this to this audience of women, and everybody is like laughing and shaking their heads—. There are things that we have in common as women, and the men didn't get it. I mean, they were in there, and they were like truly [laughter] "What were they talking about?" But it was right, because we all knew it. We didn't know each other, and the women in the room—most of us didn't know each other—but we absolutely knew that. Because most of the women there were in positions of power and authority. They might not have been on top, but they were in a high enough position that they had people who worked for them. Okay. There I felt a very strong link to the women in the room.

But the truth of the matter is that if I ever said that I felt the reason I was discriminated against was because I was a woman, I would laugh. I mean, there are times where, clearly, being a woman adds an additional discriminatory factor, and if I wasn't disabled, I would be discriminated against because I am a woman. I am a woman, and I am disabled, so I am discriminated against because I'm a woman. Do you know what I'm saying?

Young: Yes.

Heumann: But there is not a prayer that I believe it. If I did a study, a scientific study to ask, you know, to talk about discrimination and to look at why I've been denied what I've been denied, and why I will continue to be denied what I will continue to be denied. But the reason it's happening is because I'm a woman in more cases than not? No way.

Young: So if you were—

Heumann: I think Peg's too immersed in women's studies. [laughter] I don't know.

Young: So if you were to change one factor versus the other—if you were a nondisabled woman or a man with the same kind of disability, you feel that you would experience—

Heumann: If I was a disabled man, I would feel less discrimination than a disabled woman, but if I was a disabled man, I would be discriminated against in ways that a nondisabled woman wouldn't. She really believes that? Why did she say that? Did you ask her?

Young: I'd have to go back and listen to the tape. One of the things that we'll get to later is I'm talking about the relative ways in which the disability rights movement is a movement analogous to or in the same camp as black civil rights, women's rights, gay rights, trying to situate where disability fits in that. I think it came up in that context. Of course, she also felt that disability really wasn't as much of a movement.

Heumann: As much of a movement? Or had as much potential to be a movement? I mean, it's one thing to be—

Young: Not as legitimate of a movement. It's not a movement in the same right as these others. It's really a fascinating discussion. When I get it transcribed, I'll run it by you. But I think it came up in that context where she was talking about how, you know, when she reflects the discrimination—

Heumann: Ask her the following question: A women's shelter that denies a disabled woman entrance and services is denying it to her because she's a woman or because she's disabled? There is only one answer. It ain't because she's a woman, because everybody in there is a woman.

Acceptance of the disability rights movement

Young: That's exactly what I was going to talk about next. I'll come back to this when we get to Berkeley. But the receptivity of other movements accepting the disability rights movement or people in minority roles. Do you see a relative difference between, say, African American—and I know it's inappropriate to generalize—but African American responses to disability versus women's groups response to disability? Is either one or the other more receptive? Or equally receptive?

Heumann: It's a little hard for me to answer that, in part because I don't want to be judgmental. I mean, an answer like that is a judgmental answer, but my immediate answer is they're all the same. I think when you look at them as a movement, as a whole they're all the same. No one of those movements jumped out to me that says, "We're really reaching out to our black disabled brothers and sisters," or, "to our women sisters," or, "to our Latin American brothers and sisters," or, "our Asian brothers and sisters." It's not there.

I think there are people within those movements who are understanding more about our movement and are willing to learn and to be more inclusive. I definitely feel that there are those people there, and they're more there than they were before. I think that's positive. I

think that those people understand that this is a movement that is equivalent to their movements.

I think you have to be incredibly persistent and explicit, vivid, stark, to allow people to understand the kinds of discrimination that disabled, let's say women, face, and how that discrimination parallels and where it deviates from them. Because, the way I basically view everybody is they're not disabled. So to me their religion, their race, their ethnicity is irrelevant to me. No group of people has made me feel that I am welcomed into their group like I feel I'm welcomed into the disability group.

You know, when I first came into the department, I felt like I did in college and high school, which is, I would feel uncomfortable going into a room of people that I didn't know. I don't feel as uncomfortable with that anymore. I have a stronger sense of myself, and I clearly feel that difference. I think I felt insecure. Now I feel more secure about myself. There is a qualitatively different feeling for me around that, and it's a better feeling. I don't care as much about certain things as I did before.

Young: Such as?

Heumann: I wouldn't go some place where I didn't know people. I just felt too uncomfortable. Now, I'll do that more. I may not stay, but—it's hard to explain. I just don't have that same feeling of discomfort, like a real visceral high school feeling. I can relate it as a high school feeling. Like going some place where I really didn't want to be, where I didn't really feel comfortable, but I had to go there. I don't have that feeling anymore as much.

But one of the accomplishments that I've really wanted to try to achieve in this job is to try to work more effectively with the race groups, because they don't accept disability. They see disability as a weakness, as a vulnerability. They also believe, correctly so, looking at the African American community, that you have African American teenagers who are being identified as having disabilities, like emotional disabilities, being removed from regular classes, being placed in separate classes where instruction is barely going on, feeling as though overidentification is a problem, and it's racist. Overidentification is partially racist. Or, let's even say it's completely racist.

Young: You mean overidentifying—

Heumann: African Americans.

Young: —with disabilities.

Heumann: Right. Or overidentifying them in a disability they don't have.

Okay. Any place you feel you've overidentified, fine. I'll accept it's wrong, and I'll accept it's racist. But the basic premise behind that argument is that if you really are disabled, it's okay that you go to a crappy program, because we don't really have a belief that you can benefit anyway. So if you're really disabled and dumb and incompetent and can't do for yourself, no problem, you can go over there. But we really don't like it if you're not dumb and incompetent that we put you in a crappy program.

My feeling is, when they get the issue, they'll get it and say—like the disability movement is saying—crappy programs are bad for anybody, whether they have a disability or not. Our people should be getting good services whether they're black or Latin American or white and/or have a disability. To make them understand that and be arguing for quality services for all people, then they can accept the fact that one of the things that we're fighting for is not having overrepresentation or underrepresentation, which is another problem that goes on. That people that have disabilities can get the appropriate services they need, and they deserve them, and that they see as part of their responsibility as a civil rights movement to help their people get what they deserve with disabilities. We are not there. We may not be there because people are very angry about it.

It's a difficult thing, you know, because I'm white, but, on the other hand, I feel very strongly about it. When I say to people—and I say it everywhere—when I say to people that my concern is that people believe that if you're not really disabled you shouldn't be in a crappy program, but if you are really disabled, it's fine to be in a crappy program. I have not heard anybody challenge me on that. I've had people kind of go {silence}, which makes—and I might be wrong on this—but it has made me feel like people have stopped and thought, "Maybe there's something in what she's saying."

Young: Do you think another barrier to the acceptance of the collaboration is that taking groups that have struggled publicly for civil rights and for an image of strength and vitality and self-determination, that disability represents a lack of those things or compromises—

Heumann: I'd separate your words out. I'd use the word vitality and what was the other word?

Young: I think I used strength and self-determination.

Heumann: Okay, so let's take the words strength and vitality and separate self-determination out. I think that people see strength and vitality as something that they don't necessarily envision disabled people having. So to be physically strong and to have vitality, it's the same thing that you get, regardless of your color. I think there are cultural differences. I mean, I do believe that basically there really aren't societies that accept disabled people, but disability is seen differently in the U.S. and in a poor Latin American country, a poor Asian country, a poor African country. But in all of our countries, to be seen as vulnerable or to be seen as weak or not vital is something that people—they don't want to be seen that way—themselves. They want to see themselves as being strong and vital. If you don't believe that a disabled person, a truly disabled person—you know, really weak, really unable to make decisions, really needing to be taken care of by the church or by somebody—you ultimately don't believe that those people can really contribute, so maybe you don't believe that it's worth the money or the time or the energy, and that it sucks off from the legitimate movements. You know what I'm saying?

Young: Yes.

Heumann: It's deviating, it's detracting. So I think the unions and the civil rights movements and the women's movement have a better understanding today than ten or twenty years ago, but I feel like they have not yet been integrated with disabled people becoming a part of their movements. When disabled people are really in the leadership roles of those movements—African American men and women, Latin American men and women, women of different colors and different socioeconomic backgrounds, et cetera—then we'll see something different. I mean, it is fair to say that the disability rights movement is still too dominated by white middle-class individuals so that our movement does not appropriately reflect the diversity that it should reflect. But I do think it's also fair to say that this movement is probably willing to struggle more at recognizing that and making changes than the other movements are on including people into their groups who have the same color and have the same religion and have the same sex, because there is something different that divides us, and it isn't religion, and it isn't sex, it's disability.

I have to call Peg Nosek. I think that's fascinating.

V. College Life at Long Island University and Thoughts on Disability and Civil Rights

College aspirations

[Interview 5: July 21, 1998] [Tape 6, Side A]

Young: This is an interview with Judy Heumann on July 21, 1998. The interviewer is Jonathan Young. We are meeting in Judy's office in the Department of Education in Washington, D.C.

Okay. When you finished high school, at what point did you know you were going to go to college?

Heumann: Before I finished high school.

Young: So that was something you had been planning on for some time.

Heumann: It was always expected that I would go to college.

Young: Did you have particular aspirations of specific colleges you wanted to go to?

Heumann: I think I had applied to Julliard. I was interested in going to Julliard and applied there. I guess I did my audition when I was seventeen. I think I must have been a senior in high school when I did my audition. They told me that I should come back the following year to do another audition. I think that would have meant that I would have not started college right after high school.

My parents weren't convinced that studying music would be the best way for me to support myself, so that was kind of the end of that.

Young: From a financial standpoint, they just did not think music would be a prominent thing, supporting?

— 82 —

Heumann: Right. I mean, I think music and theater—a lot of people struggled in it—and I think that my having a disability would make it a lot more difficult. I continued to study voice and majored in speech and theater in college, but I think I was always looking at going to college. Were there any schools in particular? I think Long Island University, where I ultimately went to, was the school that I had thought about going to because some of the students in my high school had gone there. They said it was a small campus and it was easy to get around.

Fear of test-taking

Young: Did you want to live close to home?

Heumann: Yes. My brother had gone away to college, but it really wasn't something that I thought about. I think living away from home in the same city was a challenge because of attendant services that I needed, and no systems really being set up, and programs that I had heard a little bit about seemed to be more for people who were physically independent, which I wasn't. I applied to a couple of other schools. I was rejected by a couple of the schools. My SAT scores were not good. I did really poorly on competitive tests.

Young: That seems surprising to me.

Heumann: Oh, no. I did terribly on competitive tests.

Young: You're a very competitive person, though, I would think.

Heumann: I'm competitive in certain ways.

Young: Maybe it's more drive than it is competition.

Heumann: Right. But I think the testing issue for me was that having been on home instruction, we had no tests at all and certainly nothing competitive. When I was in special ed, we had no [competitive tests]. By the time I got to high school and was—I think we talked a little bit about this—in high school itself, tests were always a difficult thing for me. I always performed less on written tests than I did verbally. I think I told you I had failed chemistry. Got 100 on a test in the summer. Did I tell you this?

Young: No, you didn't tell me about that particular test.

Heumann: When I was in high school, I had, like, an 80-something average in chemistry. When I took the Regent[s examination], I got 40-something on the Regent. When I went to summer school, I went to a small Catholic girls' school around the corner from my house. There were two or three other girls in the class with me. The nun really liked me. I used to go there early every day. They used to give us both review of the chemistry course and a lot of tests. I did really well on the tests. Once I had gotten 100 on a test and the nun told me—Sister Mary Bourgia—the nun told me that that was the test that I had gotten 43 on.

— 83 —

Young: The very same test.

Heumann: I had no recollection of ever having taken the test. It wasn't at all familiar to me. She said to me, "You realize that if you don't get above an 80 in the Regent's [exam] in summer school, I will not be able to give you the grade that you need, that you deserve because they'll say that you went to a Catholic school and they just gave you a grade not based on what your achievement was." Really, all my test scores were over 90, and I got a 70-something on the Regent. I am so nervous about taking tests like that, that I decided my graduate school, based on a school that didn't require a GRE [Graduate Record Examination].

When I applied to Columbia, to graduate school, they didn't require a GRE, and I got into Berkeley, although they required a GRE, because of the way I got into graduate school, they didn't. So I never took the GREs. Never will take the GREs [chuckling].

Young: So did this affect your policies as Department of Education for approaching standardized testing? This is off the subject, I know.

Heumann: No. I don't think it affects my view of standardized testing as much as it affects my view of what happens for kids who are not taught how to take tests. Some kids, even being taught how to take tests, do poorly on tests. Tests don't necessarily measure the progress. But they do, in a more than significant percentage of the cases, measure kids' progress. But I really think that my problem was that I didn't take tests for so long that when I first went into high school to take a test, it just freaked me out. I had never been in a classroom with so many kids, let alone taken a test with so many kids.

I started thinking about college, I think the same time everybody else did. My rehab counselor talked to me when I was a junior in high school about going to college. As I said, I never thought about going to college out of the area. My father hadn't graduated from high school, and my mother had had very, very, very little college.

My cousins went to either Brooklyn College or Long Island University. That was kind of where we went. But I think most of my relatives went to college, at my age.

Young: Did it take on greater significance for you because your parents hadn't finished college?

Heumann: Finished college. My father hadn't finished high school. I doubt my mother finished first year. I don't think my mother finished a semester. I think she was working. I don't know, actually. To me, it was just something that was always expected, so it was expected of me and my brothers. Although my father would say it didn't matter to him if we went to college; everybody shouldn't go to college; only people who could do the work should go to college.

Nonetheless, I never thought of doing anything else. Thinking about a job without college was kind of impossible because I had taken academic [track]. I mean, in New York City at that time, you went into an academic track, a commercial track, or a general track. If you were in an academic track, it was assumed you went to college, and I was in an academic track, so it was just assumed I'd go to college.

Non-access at Long Island University

Young: When you applied, did you make it known that you were a person with a disability? Or did that just not enter into the application process?

Heumann: It certainly didn't enter into the application process. Where I went to school had no disabled students program, and the other schools that I applied to—I think Hofstra [University]—might have had a disabled students program, maybe. But Brooklyn College, I don't think did. No, at that time it was early sixties, no—mid-sixties. As I say, where I ultimately went to school, they didn't have a disabled students program.

Young: You talked about the difficulty of managing the attendant services. Were you pretty scared about going to college or basically excited? How did you feel?

Heumann: [pausing] I think I was excited about going to college, but I was also nervous about going to college because, again, the whole issue of access. Where I ultimately went to school, there was a lot of inaccessibility. The dorms that I stayed in had two steps, no ramp, and a step into the bathroom.

Young: What did you do?

Heumann: I always had to ask somebody to help me.

Young: Every day, every time to go to the bathroom, every time to get into the dorm. A pain in the...

Heumann: Yep. They didn't make the dorm accessible. They didn't build the ramp into the dorm, I want to say, until—I'm not sure whether it was after I graduated—but it certainly wasn't in the first three years. Things were just so inaccessible at that time. There wasn't a world of accessibility.

Young: There really wasn't a point of comparison. It didn't seem all that out of the ordinary.

Heumann: Not that I'm aware of. It was more inaccessible than the high school I had gone to because the high school I had gone to had a ramp, and the dorm had only two steps, so it wasn't like it was a big deal. One of the reasons why we started the disabled students program was to get things like this taken care of.

Young: What did that mean on a daily basis? Did you generally travel around the campus with a friend?

Heumann: I always had to ask someone to push me.

Young: I guess what I'm asking is did you go with people everywhere or did you just call on whoever was around when you wanted to get up the steps?

Heumann: Well, it was more likely than not that I was with somebody who was helping me get—it was a small campus. One of the reasons why I looked at the campus was because it was a small campus. It meant that the lack of access was confined [chuckling] to a small area.

Young: [chuckling] There's a good "half full" approach.

Heumann: There was the dorm, and there was, I think, two buildings—three buildings, maybe—no, maybe just two. I can't remember. No, I definitely always had someone push me. Usually I tried to get somebody that I knew to push me, but sometimes I would just ask somebody to push me.

Young: Was that something new in college at that time?

Heumann: You mean to get somebody to push me?

Young: Somebody that you didn't know. Or is that something that you had grown accustomed to?

Heumann: Well, in high school, the area was even smaller [chuckling], just one building. There, I pushed myself a little. Friends would help me get from class to class, or I would be going from one class to another and somebody in my class would help me get there. I also think there was an aide in the school, in high school.

Young: Not for you individually, just as a general function for the school?

Heumann: Yes, I think so. I can't swear to it, though. I don't think so. I remember aides in elementary school. I couldn't possibly tell you who they were in high school. In college, I had a friend who I had gone to camp with who went to the university before me. She was in a sorority, and she knew this one woman who lived in the dorm who would be willing to help me out, so I roomed with her the first year. Then, after that, I would in a modest way interview people. It was really more like trying to find somebody. I paid them a little bit of money. Of course, I made friends in the dorm. That was the advantage of living in the dorm, was that you really knew people since they lived so close. I joined a sorority.

Joins sorority

Heumann: The other thing was that when I was in camp the last year of high school, I met a woman named Judy W. I think she had graduated from Syracuse [University], or she was at Syracuse. There was this sorority at Syracuse, and a chapter of that sorority on the campus that I was going to go to. She had recommended me to that sorority. I never would have gone out for a sorority otherwise.

Young: Why?

Heumann: Because I just wasn't very outgoing like that. Not having a motorized wheelchair really was very inhibiting because I couldn't push myself well, and I was always very self-conscious of needing to ask for help or feeling like I wasn't pushing myself well. So, being a pledge in a sorority meant that I *had* to go out because there were things I *had* to do. I had to be at the table a certain number of hours a day, and I had to do a certain number of things. So I think actually that was probably a good thing.

— 86 —

Then it turned out that the sororities and fraternities controlled the student government for the first two years that I was at campus. Then, in the junior year, the more politically oriented people began to take more control of the student government.

Young: What do you mean, the more politically oriented people?

Heumann: Students were more politically involved in the antiwar movement and were involved in organizing some strikes on campus around tuition and other issues.

Young: So they weren't student government officers. They just took over the functions of—

Heumann: They ran for student government positions when I was in my junior year.

Young: Previously only people from the sororities and fraternities would run?

Heumann: I'm not sure only that would run, but they were the ones who won the seats.

Young: I see.

Runs for junior class secretary

Heumann: When I ran for junior class secretary, I lost by nine votes.

Young: Out of how many? What kind of numbers are we talking about?

Heumann: It was a couple of hundred votes. I don't know. But at any rate, I lost. Then, when I was going into my second semester, junior year, the woman who I had lost to quit [chuckling]. So I ran again, and then I was elected, so I was junior class secretary for half a year, one semester, and senior class secretary for one year.

What do you want to know about college?

Small campus setting

Young: Well, I was letting you finish with that. You talked about it being a real small campus, with a dorm and two buildings. How many students in a class?

Heumann: There were, like, sixty-five hundred students on the whole campus.

Young: Sixty-five hundred?

Heumann: Undergraduate and graduate.

Young: Pretty big, then.

Heumann: Not for a New York school. Well, it was mainly a commuter campus. The majority of students didn't live in the dorms.

Young: But all the academics fit in just those two buildings.

Heumann: Yes. I'm trying to remember. There might have been three buildings. But there were no more than three buildings.

Young: What was the ethnic or religious or gender or any other type of diversity on campus?

Heumann: It was mainly a white campus. It had a significant population of Jewish students. But there were also African American students; they had a sorority and a fraternity. Some Hispanics.

Young: How about people with disabilities?

Heumann: Yes, there were disabled people there.

Young: Mostly physical; i.e., wheelchairs? Or what types of disabilities were represented?

Heumann: Well, over the course of my being there, there were students who had more types of disabilities who came there. But my recollection in the beginning was it was primarily physically disabled students.

Use of attendants and support from DVR

Young: You made allusions to attendants. What was that like? You haven't really mentioned any attendants so far in terms of getting around the campus.

Heumann: I had different people who helped me in the dorm.

Young: Just fellow students? Nobody who was a professional attendant?

Heumann: No, students that I paid. I never used professional attendants in my life.

Young: What is involved with that decision?

Heumann: With the professional attendant?

Young: I guess I'm thinking of somebody that's—

Heumann: Paid?

Young: At least that's what they commit their life to, as opposed to, say, a student who is a full-time student and doing a little bit of work on the side.

Heumann: I think there are lots of reasons. One is that the cost was prohibitive, and there was no way of getting any money for covering it. But I think the other issue is they were so medically oriented. You know, they didn't see themselves as an extension of me. That was never an issue.

Young: You've talked about finances. How did you support yourself through college?

Heumann: I was supported by DVR [Department of Vocational Rehabilitation].

Young: Did that pay the entirety of tuition, books, room and board?

Heumann: Yes. I can't remember. It paid for my tuition; it paid for my books. I don't remember whether my parents paid for the dorm. I can ask my mom.

Young: But they wouldn't have provided any money for attendant care. That was something that came later on. Because your parents helped you out there. You weren't working to pay for the others.

Heumann: I did work, actually. I worked in the summers, and I worked as a work-study student, so I worked one year in the president's office and got paid for that, and I volunteered in the reading clinic, and I volunteered in a community clinic. As I said, I worked in the summers and got paid in the summers. I'm trying to think. Then I worked for Dr. [Theodore] Childs, when the Disabled Students Program started. I might have gotten paid doing some work there. I didn't earn a whole heck of a lot off of work-study.

Young: I don't think that has changed.

Heumann: Right.

High school versus college

Young: How about your courses? Was it more challenging than high school or more of the same? What was your impression of the academic side of college?

Heumann: It was more challenging than high school. I took speech and language classes and the basic history and sociology and language and math and all those sciences. Majored in speech and minored in education. I think I enjoyed a lot of college. I liked graduate school the best, from an academic perspective, by far.

Young: What didn't you like about college that you did like more in graduate school?

Heumann: In graduate school it was the field that I was in that I really liked. I liked public health, and I liked the courses I was taking. They made sense to me, and they were valuable for me to do the work I wanted to do. I really did learn from them. In college, you know, some of the courses were of interest to me. Some of them you just had to take. But a fair number of them were of interest.

But I think when I did finally go to California to go to graduate school, I also had a motorized wheelchair and at that point, then, I was on SSI [Supplemental Security Insurance], and I had IHSS in California, In-Home Supportive Services, so I had money to hire somebody for six or seven hours a day, which made it very different because I could have somebody in the morning and somebody at night.

More on attendant needs

Heumann: But at UC Berkeley at that time, also, the campus wasn't very accessible, and the bathroom in the building that I mainly went to school in didn't have an accessible bathroom, so I had to go to the [Physically] Disabled Students' Program every time I had to go to the bathroom and ask somebody there if they would be willing to help me.

Young: Where was the Disabled Students' Program at the time?

Heumann: It was behind Top Dog.

Young: On the north side of campus?

Heumann: You know where Bancroft is?

Young: Okay, Bancroft, okay.

Heumann: Towards the hills, on the other side of Telegraph, going toward the hills. Across the university.

Young: So you had a fair bit of traveling, then, just to go to the bathroom.

Heumann: Oh, yes. Definitely.

Young: Gee! We'll get back to that a little bit more. In college, I know you got involved politically. Was that where your heart was? Or was your heart more in the job that you did and the people you were with? What really drove you in college? What was your priority?

Heumann: I studied, definitely. My priority was school. But then I also did numbers of things that were related to school. I worked in the Reading Clinic, and I worked with some friends in setting up a community after-school program, and I liked both of those things a lot. But they were relevant because I was interested in being a teacher, and that gave me an opportunity to get work experience. Working in the Reading Clinic was something I needed to do for part of my coursework. I had to work in a clinic or someplace like that, a community program.

— 90 —

Teaching as a career goal

Heumann: I did that also. I worked in a hospital, I think.

Young: When did you become interested in teaching?

Heumann: Before college.

Young: Why teaching?

Heumann: I don't know why teaching. I was interested in it. I thought that I liked kids, and a lot of my family were teachers, my cousins. Most of them who went to college—not all of them, but most of them—became teachers.

Young: Of course, there was the big lawsuit toward the end. Did you have any sort of forewarning about that when you entered the program of education?

Contacts ACLU

Heumann: Sure. There hadn't been any teachers that had been hired who used a wheelchair, so I had actually called the ACLU [American Civil Liberties Union] before anything had happened and said, "I'm interested in being a teacher, but I know there are no people who have been hired as teachers. What do you suggest I do?" They said, "Well, just go ahead and take the courses that you need, and if you have a problem, call us." [sneezes] So when I [sneezes]—excuse me—[sneezes]—excuse me!

Young: Bless you.

Heumann: So when I did have a problem—what actually happened was I was interested in studying education, but friends of mine in high school had told me—

[Tape 6, Side B]

Young: So you had high school friends who told you not to tell Voc-Rehab you were interested in teaching.

Heumann: Right.

Young: Because they knew that Voc-Rehab wouldn't support it?

Heumann: Because at that time, whether fact or fiction, it was believed to be fact that you had to be able to show rehab that there was someone who had a disability similar to yours working in a profession like the one you wanted to study for.

Young: You're kidding.

Heumann: You're a baby [chuckling]. You don't know all these things [laughing].

Young: I admit naivete. Literally, you needed to point to an example.

Heumann: That's what people told me. So they said, "Don't tell anyone you want to be a teacher because if you tell them you want to be a teacher, they'll tell you you can't be a teacher because—"

Young: Nobody else is.

Heumann: "—nobody else is a teacher who's in a wheelchair."

Young: So much for the visionary notion of "be what you can be," huh?

Heumann: That was kind of an inherent conflict with what we were told. That's why I think a lot of the work that I began to get more involved in around the politics of things was because it was becoming clearer and clearer that this concept of an American dream really was not true for myself or for other people that I knew. There were lots of barriers and limited expectations and limited opportunities.

Career counseling in high school

Young: You talked about high school. I asked you something about reaction of teachers in your high school, and your high school teachers didn't really seem to give any particular message like that. They did support you.

Heumann: Yes, but there never was a high school teacher who had a disability. We never discussed what I wanted.

Young: Okay. Well, I guess, the topic of a career...

Heumann: I didn't have any career counseling.

Young: Right.

Heumann: I joke about the only career counseling I ever had was the speech therapist, Mrs. Malakoff, who told me when I was in the fifth grade that I would be a good speech therapist because I understood the kids who had cerebral palsy and I could get an MRS degree and work in a hospital. That was really kind of the extent of the counseling I got. I asked what an MRS degree was and she said I could find myself a husband and get married.

In high school, I did know a high school student who had a disability, who wanted to be a Spanish teacher, but she had a heart problem. She didn't use a wheelchair. Not all the kids in my class used a wheelchair, in my homeroom, especially at homeroom. Actually, more of the kids didn't. More of the kids had very minor disabilities. You weren't quite sure why they were really there.

There was a guy named Barry Foster. He had arthritis. There was a guy named Steve Goldman. He had polio. Linda Slone; she had polio, was in a wheelchair. Karen Rose; she had polio. But then there was my friend[s]—like Nancy and Mimi. We never knew what Mimi's disability was, except she was always nervous. But, in her neighborhood, she didn't look as if she had a disability. There were no such things as IEPs or anything at that time.

Young: IEP?

Heumann: Individualized Educational Program, what you get now under IDEA [Individuals with Disabilities Educational Act]. There was no such thing then. It was somewhat arbitrary about how you got into special ed. Nancy had a heart problem.

Young: Nothing that was really an impingement on—

Heumann: Right.

Young: —their being a teacher?

Heumann: Yes. So the students who had more significant disabilities were looking more at social work or speech therapy.

More on DVR support

Young: Did the VR [Vocational Rehabilitation] dollars have to be approved on a semester basis by the courses you took, or did you have a free rein?

Heumann: You had to submit what you were taking. I mean, VR dollars were much better then as far as what I was able to get, because I went to a private school and they paid the tuition.

Young: The courses you were taking: were they the courses you needed to take to be a teacher?

Heumann: To be a speech pathologist and to minor in education. I had two minors. I had the minor in education. I don't remember what my other minor was. But my basic degree was in speech and theater, with an emphasis on pathology. A minor in education, and a minor in—I mean a minor was four courses. Almost two years of what you took were required courses, and then you took the specialty courses.

What was very ironic was when I applied to Rehab for services, you had to take a psychological test. That's one of the things that has been changed over the years. But you had to take a psychological test.

Young: What was the purpose?

Heumann: To test your IQ and test your areas of interest. I had said I was interested in being a speech pathologist, and they said I tested better to be a social worker. So my parents said, "If she wants to be a speech pathologist, you'll pay for her to be a speech pathologist." In point of fact, you know, it's kind of funny because I really am more social-work-oriented, but there really isn't a very big difference between speech pathology and social work as far as helping professions. One has got more science than the other.

Attempt to bar from dorm

Heumann: I did well in my speech courses in college and did well in my college classes. What I liked about college was when I was involved in some of these extra programs, when I was involved with the Reading Clinic, when I was involved in setting up the after school community program. [whispering to herself] What was it called? It was the Fort Greene Community Center, I think is what it was called.

Tony Mellie was the guy who did a lot of the work on getting this after school program set up. I had met him—I'm not sure if it was through student government—through classes. Anyway, he was a nice guy, and he was very community oriented, and so I did work with him. I was involved with that, the Reading Clinic, I was involved in student government, I was involved in sorority, I was involved in working with other disabled students and getting the Disabled Students Program together.

But I was also having some ongoing problems that were there. The first year I lived in the dorm, I had my friend Tony, who is still one of my good friends, who helped me out. I was also able to do more in those days, for myself.

Young: In what sorts of ways?

Heumann: I used to wear braces at that time. I could get from the wheelchair onto the bed, but I couldn't get my braces back on, myself, and so I needed help putting them on. I couldn't get up the step, but once I had gotten up the step, I couldn't get down the step by myself, but I could help myself more in the bathroom than I can now. It might have been because I was wearing braces at that time.

But the second year I was to come back to the dorm, I had this woman who was from Egypt who was going to help me out. I got a call from the head of the dorm, like a week before school was supposed to start, telling me that the woman who was going to help me out was no longer willing to help me out, and so I couldn't move back in the dorms.

I called the president of the board of the school and told him what had happened. I did go into the dorm. The dean brought me to the dorm, and I got another attendant. But I was the first student in a wheelchair to live in the dorm.

Young: All the others had lived with families?

Heumann: They lived in Brooklyn, and they just went home.

Young: Did you have to get a special concession to do that the first time around?

Heumann: No, I mean, I don't know what happened.

Young: It wasn't prohibited; it was elective that people hadn't done that before?

Heumann: Yes, yes. I mean, it cost more money to live in the dorm. The other people that I knew who went there could drive, so they drove home. But I couldn't drive, so it was convenient also to live in the dorms. It was both socialization and convenience. But I went home every weekend because I felt very uncomfortable staying in the dorms on the weekend.

College dating

Young: What went on on campus on the weekends?

Heumann: Nothing I ever really participated in. Some people went home because it was more a commuter campus. People dated and did things like that, but I was never included in that.

Young: Was it a party atmosphere?

Heumann: Yes. As I said, I usually left on Friday and came back Sunday. One weekend I was there, and I remember some guy. It was kind of a liberal school because we allowed guys on the floors between certain hours. I remember some guy knocking on the door and asking me if I knew somebody. They had an extra guy downstairs and did I know somebody who was looking for a date. That's kind of what my vision of college was like as far as dating was concerned.

Young: So sex, drugs, and rock and roll you just kept an arm's length from?

Heumann: Well, as far as with the college kids. I mean, I had boyfriends and stuff from outside of college.

[tape interruption]

Heumann: I dated other guys but not from school. I went out with guys that I had met through camp or other disabled friends.

Young: Was it a different experience than in high school?

Heumann: Well, I was older, so [chuckling] yes, it was. Living on the campus was different. The first two years, the way our dorm was—

Young: I was thinking of dating in particular, but go ahead.

Heumann: I dated more than I did in high school. In high school, I only dated when I went to camp, at camp. When I went to college, I didn't do a lot of dating there either, but I did more. The first two years, we lived on floors where we had a room, so it was two of us; but then the next two years they had apartments. There were three or four of us who lived in the apartments, but we had two bedrooms and a kitchen, so it was more social. Then I moved into my own apartment with some other friends. I never dated anyone from the nondisabled community at the university.

Young: To what extent did your relationship with your parents change? You didn't have a complete break in the sense of being gone for months on end. Being there only on weekends would make it different, still.

Heumann: Yes. I mean, I talked with them frequently, and I went home on the weekends. My father used to pick me up during the week and take me to the city for voice lessons. I didn't sleep home during the week, like, four or five nights a week, but I did on weekends and most holidays.

[tape interruption]

Young: Do you think that the disability experience affected your separation process? You talked about the typical separation process. Was that delayed in any sort of way?

Heumann: Certainly, my options—or what I considered my options—I felt were more limited because of my disability. I needed my family, both emotionally, which I think in good family relationships you need that. But physically I needed them because there were just things that I couldn't do without them.

Initial foray into politics at Long Island University

Young: You have alluded a couple of times to your getting involved in politics and the DSP as being your first big issue. Tell me a bit about how you—

Heumann: Disabled Students' Program?

Young: Right.

Heumann: The first political step I got involved in was the student government.

Young: Okay. I was under the impression that DSP came earlier.

Heumann: No.

Young: Tell me the narrative history of your political involvement.

Heumann: When I think of when I first got involved in something that I would call really more political, that would be when I ran for office, for student government, because there I was a disabled person, but I was running for class secretary. I was definitely doing work with the Disabled Students' Program. But I think in college, I was involved with the student council, I was involved with more of the political work that was going on on campus.

There was a strike that had been organized, where the campus was shut down because of a tuition increase, and I was involved with that. There were antiwar activities that were going on, and I was involved with that. I wasn't ever the front-line person in those activities, but I was definitely involved. I still didn't have my motorized wheelchair. I had a discussion with the guy who had been the senior class president, I guess toward the end of my senior year. He had said to me that he really had thought that because of my disability, I wouldn't have been able to do the job, but that he realized he was wrong and I had done a great job.

So it was always something that I always knew was a part of what was happening.

Young: That the disability was part of what was happening?

Heumann: Yes, the disability was still always being looked at and I wasn't just the junior or senior class secretary. They were wondering what I was going to be able to do. But within a short period of time, that, I think, was dealt with. But still people had those thoughts.

I was never convinced that the reason that I lost didn't have something to do with the fact that I had a disability because I had lost by such few votes. Of course, there were slates and I wasn't on one slate and this woman was on another slate, so that certainly was part of it.

Young: What were some of the principal issues that you addressed—not necessarily you personally—but as secretary, what things were you involved with?

Heumann: Oh, God, that was so many years [chuckling] ago! That was thirty years ago. Just the general activities that were going on. As I said, there was the strike that was going on because of the tuition issues, so I was very involved with what was going on with that. Just the general operation. I also was at that time working in the president's office and was a receptionist in the president's office. But I had a good relation with President [Alexander] Aldridge.

Importance of technology

Heumann: I mean, I was gradually moving up, getting to feel a little bit more secure about myself. I think not having a motorized wheelchair and being in such an inaccessible environment really continued to be problematic. The public transit systems weren't accessible. I couldn't drive. All of these opportunities to break out and do other things were more difficult for me to do, so, while I was feeling like I was moving ahead, I also was feeling like I was continuing to be limited in what I was able to do.

Young: The importance of technology just keeps coming up over and over and over again, especially with respect to the motorized wheelchair but then also the access. It really underscores the whole idea of it's not just the individual but it's a social phenomenon. There need to be things to enable the person to—

Heumann: The way people saw me was impacted significantly by what I couldn't do, and I really couldn't do it. I couldn't get up. That's why I hate this stuff of disabled but able. I hate those plays on the word. To me, disability is an inability to do something, and I have an inability to walk. The inability to walk wasn't a problem or wouldn't have been a problem if there were ramps and not steps, and doors that were wide enough. But even with those barriers not being there, I still would have needed additional assistance because of the significance of my disability.

So because personal assistant services were something not typical, because the access was not good, I was continuing to have to rely on people to do things that other people didn't need to rely on people for. It continues to put you in this position of appearing as if you're unable to do things that in fact I was able to do. That's why this issue for me of having a handicap versus a disability, or being handicapped by—because I certainly was handicapped at that university. Probably less handicapped at that university than many other universities because the size, the smallness of that university, was very helpful. UC Berkeley without a motorized wheelchair would have been impossible.

Young: I realized that.

Access a societal problem

Heumann: A lot of people do that, but it certainly would have been more psychologically traumatizing. When I was at the university, in my junior and senior year I was more comfortable; I was becoming friends with more people. I was friends with some of the people who worked at the paper. The newspaper was a good newspaper. It was, I think, probably an atypical college newspaper. A lot of the people who worked at the newspaper when I was there actually are reporters now in *Newsday* and set up their own publications and things in New York.

One of the people did a series on the problems of access on campus and how that needed to be dealt with. They interviewed the dean of the School of Psychology, who said that he felt it would be better for disabled students not to be going to school at the university because the access was so bad that it caused psychological problems for the students.

Young: He said that it would be better because it was traumatizing on the other students?

Heumann: No, disabled students, that we had all these difficulties. Instead of saying the university should have had an obligation to make itself accessible, his solution was have us not be there. We said this is ludicrous; the solution is we need to be here, and they need to take care of the problems.

Economic supports for people with disabilities

Young: It points up an interesting tension that I know we've talked about before, not in the course of the interview, and that is in the history of the disability rights movement, there is the discussion about moving away from the medical model, that it's not the individual but it's

a society problem. But what you were saying before is that there *is* a functional basis to disability.

Heumann: But it still is a societal problem. In this society, if you're a veteran and you become injured in the line of the military, it is accepted that you'll be compensated. The compensations are based on your level of injury. Now, what a veteran doesn't get is the barriers removed from the general society. What the veteran did get and does get are economic supports to compensate for the loss of certain parts of their body.

Young: Right.

Heumann: So if I lived in an environment where there were no physical barriers, the economics would be there for me to be able to assist me in performing those tasks that I can't perform by myself. If I were to become disabled today, as a veteran, I would be existing in a society where there were significant barriers that had been removed, and I would have the financial wherewithal to be able to purchase the assistance that I need and do all these other kinds of things so that the needs that I had would be more invisible. My needs become more visible when I have to ask people for [help]. We're in a society here where asking people for help, as a rule, is something that is not really considered appropriate.

Young: What you're describing, though, in the case of the veteran, it's not enough simply to have the barriers removed; there needs to be financial compensation?

Heumann: For certain levels of injury.

Young: For the levels of injury, then, that <u>are</u> rooted in the body. I think that's a tension that some people want to push it to an extreme where it has nothing to do with the individual body; it's only society.

Heumann: I understand, but what I'm saying to you is that a fair-haired person, a fair-skinned person who has to be outside all the time puts sunblock on and a hat. Nobody thinks anything of it.

Young: Sure.

Heumann: But a person who has a more extensive need, it is seen as being different because it's more atypical. I think equally important is that we haven't built into the system the kinds of various supports that you need to make these needs invisible. I'm not talking about not acknowledging them in a very public way, because I think having a disability isn't being part of a movement; it's to acknowledge it. But it doesn't have to become a handicap if the supports are there and barriers are removed.

But you're still thinking that there is, for you—

Young: That there's what?

— 99 —

Disability issues and civil rights

Heumann: A tension between—what's your perspective on this?

Young: My perspective is based on a research experience of looking at, in part, supporting the ADA [Americans with Disabilities Act] and in explaining why the ADA is necessary, pointing to the need for greater Social Security payments and more healthcare benefits which, as you know, didn't really have anything to do with the ADA, but there's emphasis on things that are provided on the basis of a physical or mental impairment. The rights model pushes in the direction of saying removing physical or whatever barriers in society and give people an equal chance to just go out and make it on their own, so to speak.

I think some critics would like to say, well, which is it? Which do you want? Do you want to have the equal opportunity in society or do you want to have health benefits or income payments because of your disability? My position is not that they're exclusive but that I don't think people have really put them together.

Heumann: I try to put them together all the time.

Young: People talk in some ways about one or the other but not together. So that's kind of what I'm getting at.

Civil rights model

Heumann: Let me see if this is in part what you're also talking about. See, I think that the traditional civil rights model talks about removing barriers, and the removal of barriers—you know, *Brown v. The Board of Education* —the barrier you're removing is denying the person an opportunity to go to a school and all of the supports that need to take place to facilitate that integration happening.

But when we're talking about individuals where the discrimination is more than just what discrimination has been in the area of race—

Young: A willful denial.

Heumann: Well, there's willful denial in both cases, but removal of the willful denial does not enable all individuals to have equal opportunity. So the issue of the bus is a perfect example. We did agree that you could not honestly say to somebody, "You have the opportunity to get on the bus. You can crawl up the steps." We didn't consider that to be equal access. But I think that what really happens is that as the needs that we're talking about impact a smaller and smaller percentage of people, that we don't necessarily have the full base of disabled people there either, really supporting the argument because in part I think what's happening is people are trying to pass. So it's like, well, if you remove the step and you put a ramp there, a lot of people have access that didn't have access before. Of those people who need the ramp, most of—

— 100 —

[Tape 7, Side A]

Young: You were using the bus as an example of the process of making—

Personal assistance services

Heumann: See, what goes on here right now is we have a civil rights perspective, which is civil rights doesn't cost money. I don't have difficulty with that. Well, I think we need to have further discussion about the different needs that disabled people have, and is it a civil right to get on a bus but not a civil right to get personal assistant services? The reason why we don't equate them the same is because we believe that we can pass the cost of one off to an entity called the Department of Transportation because we compute it out and we say it really only costs this much money over the course of a lifetime of a bus; it's insignificant and therefore—

But in the case of a person who needs personal assistant services, we don't call it a civil right, as a rule, because we don't feel comfortable assigning that responsibility to an entity. You know 504 and ADA really better than I do, on a substantive level. But personal assistant services is not equivalent to interpreter services. Why? I mean, to me it's not equivalent because of the personal nature of the service. An interpreter service—it's not that it's less expensive because, quite frankly, interpreter services are more expensive.

Young: Sure, it's forty dollars an hour.

Heumann: Right. But we say that a reader service, an interpreter service is a service that has to be provided, but we explicitly say that there is no requirement to help feed a person, to help a person go to the bathroom. That's explicit, right? Why is that? It's illogical.

Definition of a civil right

Young: What does it mean to you to say something is a civil right? If you say that getting on a bus is a civil right, what does that mean?

Heumann: It means that the average person in this country—if there is a bus that comes into their neighborhood or they go into a neighborhood where there is a bus—cannot be denied the opportunity to get on that bus because of race, sex or disability, or class or whatever. We have moved by saying that in order to enable a disabled person to get on the bus you cannot just say that we have removed the barrier, which says you are not allowed on the bus, verbally.

We've acknowledged that it's meaningless if, in fact, you don't provide a remedy. But we've said that if the remedies cost too much, you don't have to provide them. If it's an undue hardship, you don't have to provide it. We say, well, we really don't invoke undue hardship because how often has undue hardship really been invoked? Very infrequently. But I think this is an area that desperately needs significant discussion. Look at IDEA as an example. IDEA came about because states said that they didn't have the same responsibility to disabled children as they did for nondisabled children in the area of education. The kids cost more money, and the federal government will provide additional funds to help you provide disabled kids with a comparable education.

We never did that in transportation. So we have these kinds of holes in the policy.

Young: I think part of the trapping, too, is that we get tangled up about the definition of disability, confusing natural right versus civil right. Is it our potential as a society to declare anything that we want to to be a right? I think certain things strike people as being illogical because that's what they're accustomed to and certain things are more of a right than others.

Heumann: Nondisabled people think that it is a right to be able to go to the bathroom. They think that it is completely a right that there should be bathrooms, they should be easy to use, they should as a rule be free.

Young: It's a good point. You never think about it. There would be protests at restaurants.

Heumann: I do, and I've used it. I was on a committee dealing with the issue of making toilets accessible on airplanes. When I said it was fine with me if there were no toilets on the airplanes, people laughed.

Young: Good point, good point.

Heumann: I said to them, "Look, it is not a problem for me if you are denied what I am denied. If I can't use the bathroom and you can't use the bathroom, hey, that's equality." But they laughed at it because going to the bathroom is something, which is absolutely taken as a right. I don't know if you call it a civil right, a natural right, a human right. Whatever it is, it is something that people accept. Harlan Hahn said he wants to go into a meeting where there are no chairs in the room. When people say, "We need a chair," to say, "We didn't have the money for it."

Young: [chuckling]

Heumann: But it's those types of things that people just take for granted because the vast majority of people use it and can use it. Now, if we put the same number of bathrooms in the facility and we made the doorway three inches wide, people would protest. They would see the lack of logic in putting a toilet that they couldn't use, that would be symbolic and unusable, and stupid. But they don't see anything wrong or didn't see anything wrong—I think more people see things wrong now because—but still, it's still a very good analogy. They don't see a comparableness to saying, Well, you need to be making things which are usable and available. For me, part of it is making sure that there is a bathroom I can get into. But the other part is making sure that I can use it when I get there. I can't use it by myself.

Young: So should PAS [Personal Assistance Services] be a civil right?

Heumann: I personally think so. I mean, is education a civil right? I don't know. What do you call it? Do you call education a civil right?

Young: That's why I put the question to <u>you</u> because the ADA comes through and some people were saying this isn't a civil rights issue. But part of the success of the ADA was that it was presented as a civil rights issue. I think sometimes we presume civil rights are more absolute than they really are, and people don't realize—this is what I'm saying: people that are opponents think that civil rights are somehow natural and set in stone before the age of time, and don't see the way in which a civil right is something that we have socially agreed upon, whether tacitly or assertively.

So when you talk about something like PAS being made a civil right, people kind of recoil because it's somehow unnatural, but don't realize that all these other ones have been constructed to be a right. That's the idea I was getting at.

Heumann: People, I think with the interpreter issue, don't necessarily believe that it should be a service that people can get, whatever we call it.

Young: Right.

Role of society

Heumann: Now, on a certain level we can skip the terminology. The question is: What role do we believe society should play, and which corners of the society should be involved in helping to facilitate certain things happening? In this country, because we so much have this philosophy of independence and "pull yourself up by the bootstrap" that anybody who needs above what some mythical group out there says you have a need for—

[to another] Is that Michael?—and because we don't deal with this issue of who pays, it constantly puts the person who needs the money in a compromising position. We keep passing the buck to somebody else. It's this one's responsibility; it's that one's responsibility. Someone's got to be given responsibility, make the school responsible. When you make the school responsible, then people are annoyed because it's taking funds away from other kids. You can get into a whole discussion is there a certain level—

[tape interruption]

Heumann: [back to microphone]—and above that level that someone else should be stepping in? Absolutely up front and direct. There are in other countries—and here in the U.S.—skip other countries. If you're a veteran, you get your first car and the accommodations for free. Your second car, you get your accommodations for free. Because the accommodations are something that they recognize. Maybe it's illogical; maybe every time you need a car, if you get it once, you should be able to get it twice and a third time. But there is some logic in saying that we're looking at covering the additional costs. What are the additional costs? We should cover the additional costs. Make it less painful.

VI. Vocational Rehabilitation Support Through Graduate School; Growing Awareness of Disability as a Societal and Environmental Barrier Issue

Experience with vocational rehabilitation

[Interview 6: October 28, 1998] [Tape 8-1, Side A]

Brown: This is an interview with Judy Heumann. The interviewer is Susan Brown. We're meeting at her house on Connecticut Avenue in Washington, D.C., on October 28th, 1998.

In earlier interviews, you mentioned talking with a Rehab counselor when you were a junior in high school and that Rehab paid for at least part of your schooling—tuition and books is what I remember you saying. When did you first become involved with the Rehab system?

Heumann: It was either in my junior or senior year. I think it was my junior year. I had at least one meeting with them in my junior year, where they came in to tell me what Rehab was, and then I applied to Rehab, I think, in my senior year.

Brown: So did they come and get you out of high school and said, "This is a program that everybody needs to know about"? How did you really find out about it?

Heumann: I didn't. They come to you. I was in a regular high school but in a special homeroom for disabled kids. I know I didn't contact them. I don't exactly remember, but I definitely remember meeting with them. It was a man, and I remember him telling me what Rehab was, and I guess what the process was.

Then, when I was a senior and was applying for school, at some point in the senior year I applied to Rehab and had to take a psychological test and had to meet with them to talk about what I was interested in. After I took the battery of psychological tests, I had told them I was interested in being a speech pathologist. They said that the tests showed that I should be a social worker. My parents basically said, "If she's interested in being a speech pathologist, you should support her to be a speech pathologist."

But they paid. I went to a private school. They paid for private school tuition. I think they paid for everything, actually—my dorm, my books.

Brown: What were your initial expectations of the system? When that man presented it to you, what did he tell you you could expect them to do?

Heumann: I don't remember at all.

Brown: Were you surprised that they paid for your tuition and your books?

Heumann: No. At that point, there wasn't a controversy around Rehab like there has been over the years, at least nothing that I was aware of. Basically, those of us who were Rehab clients did better than most other people because at that point they weren't as restrictive. The law was moving in the direction of serving individuals who had more significant disabilities. I had one of those. So I think that was probably good for them.

I guess one of my recollections was when I went to take the psychological exam, I had this psychologist who—I remember one part of the exam I had to do something timed, like rearrange blocks or something, to copy the design off a picture, and I started before he pushed the watch—he freaked out. I remember thinking, "This is too bizarre."

Friend of the court request

Heumann: But anyway, I studied to be a speech pathologist, I was interested in being a teacher. I had to send my grades in every year, and I talked to my counselor, like, once a year on the phone, and never told them that the reason I was taking courses in education was because I was interested in being a teacher. They never knew that until I took my exams and was failed on my medical. I guess they started reading it in the paper the same time as everybody else did.

When I had that lawsuit, I asked Rehab if they would come in as a friend of the court, and they wouldn't.

Brown: Who did you ask, your counselor?

Heumann: Yes.

Brown: Did you have the same counselor the whole time you were living in New York, do you remember?

Graduate School Support

Heumann: To the best of my knowledge, yes. But Rehab paid for me to go to graduate school, so I personally did very well by Rehab. They paid for graduate school—California paid me—and they paid for my internship, and I did it in Washington.

Brown: Who paid for that, California?

— 105 —

Heumann: California. When I was in New York, New York Rehab. When I went to California, California Rehab picked me up, and they paid for my tuition, my books, and I had a stipend. Rehab had a stipend as a rehab agency, and so I was eligible for a stipend.

Brown: This was the whole time or just in New York, when you were in school?

Heumann: No, this was just California.

Brown: New York didn't have a stipend.

Heumann: No. But New York paid for my books. I don't think I got an allowance in New York. They paid for my tuition, my books, my room and board. And then, when—I think—when I became a junior in undergraduate school in Brooklyn, I moved into an apartment in the dormitories, but I don't believe I got a stipend for food.

Then in California, I had a stipend for a while.

Brown: How much was it? Could you live on it?

Heumann: I was on benefits also.

Brown: Could you live on the combination of benefits and the stipend?

Heumann: Right, because I had SSI [Supplemental Security Income] and attendant services and a stipend.

Then, when I went to do my internship, the state agency in California paid for my airfare back and forth, and they paid for the rental of a van, the rental or purchase of ramps for the van, and they paid for a driver who took me to and from work.

Brown: While you were here in D.C.?

Payment for driving evaluation

Heumann: Yes. They paid for me to get a driving—actually, New York paid for me to get a driving evaluation—and California paid for a driving evaluation.

Brown: So you had two different evaluations?

Heumann: Years apart. The one that I did in New York was just to teach me how to drive a regular car with hand controls. That was useless.

Brown: Why?

Heumann: Because I'm a quad, and I couldn't transfer in and out of a car and I wasn't strong enough to use the hand controls.

— 106 —

Brown: Was the balance a problem as well? There wasn't anything to hold onto in a car?

Heumann: Right, yes. Actually, I may have been using my braces when I took my driving in New York. My balance wouldn't have been as much a problem. I think I was, actually. My driving wouldn't have been as much a problem. When I was in California, I went for my driving evaluation, like, in '77 or '78, in Texas, because they had a program in Texas to evaluate people who had more of my level of disability. They paid for me and a personal assistant to go to Texas. But the guy said what I needed wasn't available yet, that I needed to wait for about ten more years.

Actually, Rehab did start to evaluate me again for driving in the 1990s. Now, that time I had more problems getting evaluated. They finally agreed to do the evaluation, and they had the type of vehicle that I could have learned to drive from, but there was only, like, one in northern California. By the time I had gone through an appeal to get them to pay for it, and tried to work out a schedule with the company that canceled a couple of times because—and there was one guy, and things happened—actually, nothing ever worked out. Then I came to D.C. That was the end of that.

Expectations from Rehab

Brown: Going back to your earlier experiences with Rehab, what expectations did you feel that the Rehab professionals you worked with had for you?

Heumann: That you go to college and get a job.

Brown: You felt that seemed completely fine with you, that that was what everybody just expected of you in the Rehab reality?

Heumann: Yes. They would not have paid for me if they didn't think I could get a job.

Brown: Do you know how your family felt about your experiences with Rehab?

Heumann: Except for that one incident, where they had to tell the counselor that I should be able to study what I was interested in, I think everybody felt very lucky that they were putting so much money into my schooling, because it was a lot of money.

Brown: Did you have higher expectations of yourself, then? Was there any sort of pressure on you that you had to go and you had to succeed, or do you think you would have had all that sort of feeling for yourself anyway?

Heumann: I don't feel—

Brown: If you or your family were paying for it.

Heumann: Well, in my family there was always the expectation that you got good grades. You had to keep a certain level of grade in order to get the money from the state, but that never really was a concern to me because I was more concerned about my parents if I didn't keep my grades up than I was about Rehab. I never thought about it, really.

— 107 —

Lack of job development

Brown: From your current vantage point, how do you overall assess the professional rehabilitation that you received in your early and college years?

Heumann: Rehab for me was not a place that gave me either a lot of job counseling or helped me find a job. I found my jobs all by myself.

Brown: Was that something you had expected them to do for you, or something that you expect in your position now? Is that something you would expect Rehab to do for people?

Heumann: I always knew that one of Rehab's purposes was to help people find jobs, but even at that point, people were complaining that the agency couldn't really help people find jobs. It wasn't known within the disability community as really helping you find a job. But it was known as helping you be able to get different things that you needed. Certainly, from my vantage point the agency might not have given me everything that I needed help with, but they certainly made it possible for me to do things that would have been much more difficult for me to do by myself. It would have been a lot of money for my parents to have to pay.

I actually also qualified for student aid. I had a student aid job in the summers. But that was difficult. I had to kind of fight to get that program.

Brown: You had to fight to get that program, or Rehab did?

Heumann: No, I got that on my own.

Brown: And that wasn't Rehab related?

Heumann: No.

Brown: That was through your college?

Heumann: Right.

Brown: We'll come back to that. Is there anything else you'd like to say about early experiences with Rehab before we move on?

Heumann: It was unfortunate that they were not more advocacy oriented and that the agency didn't really work with you on helping you to look for the kinds of jobs that you'd be interested in. But the bottom line is if I hadn't gotten their money along the way, I don't know what I would have done. I was lucky that I was able to make the system work for myself and that Rehab gave me the money to get the credentials I needed.

— 108 —

I think it was better then than it is today. Rehab in most states doesn't pay for you to go to a private school. In many cases, it doesn't necessarily pay if you're going to higher education, although in my current job that's one thing that we're working on changing because it's such an important thing, going on to higher education.

But it served me well. With all its problems, it served me well.

Thoughts on disability as a child

Brown: Did you think much about disability as a child? How did you think about it?

Heumann: What do you define as a child?

Brown: I would say up to high school, but you can define it however you want.

Heumann: I probably started thinking about disability when I was very young because how could I not have thought about it in some, at the very least, abstract way? You know, getting sick and leaving home and being in the hospital. Certainly, that, in and of itself, you know, what's wrong? Why can't I be home? Then when I came out of the hospital, I couldn't do the same things as I had done before, and now I had a brother. So I had to be thinking about it, however you think about things when you're two and three.

But I remember when I was four, my parents had me go to the Rusk Institute. I think it was for three months. I would stay there from Monday through Friday. They would bring me back Monday morning and visit me on Wednesday and take me home Friday night. That was the first time I was ever around other disabled people. Actually, I frequently say the first time was when I was in special ed class, but I realize that's not true. It was when I was in the rehab hospital.

I remember a little bit of, like, flirting with the guys in the wheelchairs. But I was younger. Most of the people were older.

Brown: Were they all polio?

Heumann: I have no idea. I don't think so. No, that would have been through the early fifties, so I assume they had some spinal cord injured people there, and others. I don't remember per se. But there were big guys in wheelchairs. Rusk, I think, was known for doing more than polio.

So I remember that. I remember falling out of my wheelchair.

Brown: At Rusk?

Heumann: At Rusk, because they didn't tie me in, and I didn't have good balance. I remember my parents being upset that I had fallen.

Brown: Did you get hurt?

Heumann: I hurt my chin. I didn't like having to come back on Monday mornings. I used to cry a lot. That's about all I remember about that.

You know, again, when I was supposed to go to school when I was five, I couldn't go to school because I was in a wheelchair. That clearly had an effect on me, even though, again, it really feels to me like it was more not understanding what was happening, just that things happened and that other things didn't happen.

Reactions towards people's view of her

Heumann: It wasn't until I was eight or nine years old that I remember reacting to people's views of me. I had gone with a friend who was pushing my wheelchair up the block to go to the stores, and some kid came over and said, "What's the matter with you? Are you sick?" I remember, like, wanting to cry. I think that was, like, the first time that I remember having some kind of an emotional reaction around my disability because of how people were reacting to me.

It was kind of curious because years later I had met this woman named Karen Paulsen, who was a researcher in Stockholm. She had done some studies which showed that disabled children started realizing that they had a disability around the ages of eight or nine. I remember thinking about that and going, "Oh, wow, that's when it happened to me also."

The older I got, the more the issues were around disability because the more I was aware of needing help and not necessarily getting it or not necessarily getting it in a way that people wanted to be giving it—so a more conscious feeling because, again, I'm sure it was going on earlier—but a more conscious feeling of having to weigh and measure what I asked for, when I asked for it, how I asked for it, how needing assistance had to be measured up.

I define it as—there are five things that you would like, and you can't do them all by yourself—so having to prioritize things that others wouldn't need to prioritize at all. You would just do it, because they're not big things.

Peer acceptance harder with teen years

Brown: You were saying that it got harder as you got older and there were things like birthday parties, and you mentioned people carrying you into their houses. Did people stop inviting you to birthday parties?

Heumann: Oh, no.

Brown: Or as soon as you got there, it would be awkward because there were other kids who didn't know you that would treat you differently?

Heumann: Right. I mean, I'm still friends with people I grew up with in that neighborhood, so no one didn't invite me because of my disability.

Brown: What did you mean when you said it got harder when you got older?

Heumann: Well, because there would be kids other than from the neighborhood who would come to the parties. They didn't treat me the same way, so I felt more uncomfortable being, like, the only disabled person in the group and was obviously self-conscious. Then, when we would play games like spin the tail on the donkey or—not spin the tail on the donkey.

Brown: Spin the bottle?

Heumann: Spin the bottle and post office. That was always very uncomfortable for me. I mean, it probably would have been uncomfortable for me even if I didn't have a disability because I didn't know all the guys in the group. But I definitely felt like the guys were not, like, looking at me as someone they wanted to spin the bottle with or wanted to do post office with. It was kind of like this obligation. The bottle came to me, so okay. Or we had to go out into the other room. Okay. I never felt in any way, shape, or form threatened by what was going on because it always felt like they were out of here [chuckling].

When I went to religious school that wasn't a problem, in the beginning, because it was made up mainly of my cousins. So when I was in the neighborhood, it was my family. I mean, there were times when relatives—you got a feeling that people were saying things. But it was different.

[whispering] [tape interruption]

Telephone compensates for lack of mobility

[Tape 8-1, Side B]

Heumann: I stayed friends with people from elementary school. I'm trying to think about friends that I would visit. I have friends from elementary school, who went to another high school or were younger than I was so didn't go to high school when I went there. But, like, my friend Frieda, who was my best friend. She didn't go to the high school I went to. She was younger than I was. But she also didn't go to the same high school. But Frieda I was very good friends with. I would talk with her a lot on the phone.

That was the other thing that I started saying earlier, that the phone became a more important part of my life. Everybody kind of always laughs about it, but because I couldn't travel and my friends couldn't get to me, it was the only way that we could communicate with each other. We were kind of isolated in the middle of what was going on as we got older because we couldn't go in the car and we couldn't go in the bus and we couldn't as easily just go visit our friends any longer because their houses weren't accessible, and you were bigger, so it wasn't easy just to pick me up and bring me inside. It was a bigger ordeal of needing to have more people around who could help me get the wheelchair up.

— 111 —

[tape interruption]

Society's reactions

Heumann: When we went to camp, where we had more time because we would be there for weeks at a time, was when I also started talking with kids about how we felt about being isolated and how we felt about people treating us differently, looking at us differently, not talking to us but talking—

I mean, I'm going to divert for a second. This not talking to you is like—I'm fifty-one years old. Today, I'm going to a meeting at the Blair House, with another assistant secretary. They had two doors and they opened one and they needed to open the other one, and they were having difficulty. First the guy looked at me, and then he looked to Norma, and he said, "Can you help her get to where she has to be going?" I said, "She can help herself get to where she has to be going. Just tell her where to go."

Brown: [chuckling]

Heumann: It will never stop. It is that kind of thing which will never stop. But in earlier years, it was really, like, processing it and recognizing that it wasn't just me. It was that other people felt the same thing. As we slowly recognized that we each had similar feelings around issues. Some of those feelings were also that it made us sad, it made us angry, and so it was what do you do about it? Or feeling angry at not being able to get the help that you needed. Sometimes feeling that because I needed to ask for a lot of things, that there would be tension between my brothers and myself. Or my brothers would be expected to do things for me that I would have been able to do by myself, and they didn't necessarily want to do it. That's something that still goes on, even when I'm an adult. There's always a combination, like, with family, of sibling rivalry and those normal things, but then there are the additional things that go on.

Smoking an equalizer

Heumann: I started smoking when I was twelve or thirteen. I started smoking because one of my girlfriends from the neighborhood was older than I was, a year or two older, and so I would hang out with her friends because she would push me up to the avenue. I mean, "hang out" was too much of a term. I didn't hang out with her friends. I hung out with her friends if she pushed me to where they were going.

So in high school I would smoke in the bathroom sometimes, even though you clearly weren't supposed to be smoking.

Brown: Did your parents know you were smoking?

Heumann: No. My father smoked, so he wouldn't have smelled it.

Brown: Did your mother?

Heumann: No, because my father smoked. My mother used to smoke. They never asked me if I was smoking that I recall, in high school. So I kind of don't think they did.

Brown: Was it a cool thing to do? Is that why you were doing it?

Heumann: Yes. It was to be accepted by the group, to show that I could do what they did. To me, it was really, like, I needed to show them that I could do the same things they could do. It was a different kind of peer pressure. I mean, it was, of course, in the end, peer pressure. But it wasn't feeling like somebody would say to me I was a wuss if I didn't do it. It was more like I wanted to show them that I could do it because there were so many other things I couldn't show them I could do.

I think I felt cool when I was smoking. You could think about being one of the ads and blowing rings and doing different things like that. A lot of it really did have to do with this, showing them that you really could do things and maybe blow a better ring than they could blow.

Parents fight for school admissions

Heumann: My mother was definitely not into conflict around certain things. She definitely was into conflict around things like my not getting into school. She didn't mind the conflict on that. But other things, like bathrooms aren't accessible, you just don't drink. The bathroom is upstairs? You just don't do it. So it was this kind of repress yourself.

But, on the other hand, then, as I began to talk more about the problems, that's kind of the next level because my parents were involved on the issues of getting me in school and trying to get me a good education, and I needed to finish high school, I needed to go to college. Those were all things that were always expected of me. You should do another interview with my mother. Did she talk about what her expectations were for me?

Brown: Not that I remember.

Heumann: See, what I would really like to know from her is what her expectations were, how the family reacted to me, and how she reacted to me, and how she worked with other parents. That was very much a part of what let me go on to high school. If my mother hadn't organized with these parents, I would have been on home instruction because that's what was happening at that time.

Questioning environmental barriers in early years

Brown: You've talked some about how you felt about the level of assistance that you needed and the sort of prioritizing of needs and manipulation and how to get your needs met in the

best way and what can you not get done. How did you feel about strangers helping you? I guess my question is being carried up steps to go to a birthday party.

Heumann: It didn't bother me if it was people in my neighborhood or my father or family because it just was. I think when I began to really think about it as a problem was when it became more of a problem to do it. In other words, when I was young, it wasn't a big deal for somebody to pick me up and bring me inside. When I became older, it isolated me—didn't let me get into somebody's house, didn't let me do things—then, of course, I began to slowly start asking questions. Well, why do we need these steps, and why can't I get across the street easily?

Brown: When did that start? Do you have any sense of it? Or was this a process?

Heumann: A process that happened. As I got older and began to be able to, I think, make judgments and look at things and define what a problem was and start analyzing it. I began to look at issues of authority—I think to be somewhat comparative of where—my peers were becoming more independent as they got older, I wasn't becoming more independent. But I was, of course, psychologically becoming more independent. That's why things like camp were so very important, because that was the time when I could be away with my friends and do more exploring and be less limited by my disability because the camp was designed for disabled kids.

My first boyfriend was from elementary school. My first boyfriend in elementary school actually was a nondisabled kid from upstairs, Barry Foster. There's something very weird happened. I can't remember, but it was strange.

In the beginning, when Barry was my boyfriend, I remember being very proud: I had a nondisabled boyfriend.

Brown: How old were you then?

Heumann: Fifth grade. Yes, fifth grade. I started going to school there in the fourth grade, the middle of the fourth grade. The school went through the sixth grade, but the disabled kids there stayed up to twenty-one years old.

Repressing anger

Heumann: I learned also, through all these years, to kind of repress my different types of anger. I think over time repressing my anger about how I felt when I couldn't do certain things, or I couldn't get what I needed from somebody else to do it. It was like you didn't want people to be angry at you, in addition to everything else that you were having to balance.

But, over time, I was able to get angry at the environment and how people responded to me and other friends of mine. I think the more I was in high school—even though high school itself was—I think most people remember a lot about high school.

Brown: Most people do?

Heumann: I think so. I don't remember. I do, certainly, remember; but when I think about high school, I think about being afraid of being in the classes with the nondisabled kids. Always feeling uncomfortable. Having to go to the bathroom and not being able to get help to go to the bathroom. I remember once I had to go to the bathroom really badly, and there was no one who could help me, and I wet my pants. I remember sitting in the classroom totally freaked out because it had gone onto the floor, and hoping that nobody would notice what had happened until I was gone and the next class was there, and then nobody would know who it was from. Those kinds of things.

In high school at a certain point I began to become, like, class president for my homeroom. It was always these strange things. Like, it was coming back into the homeroom and feeling comfortable with the kids there; going out into the regular hallway and into the regular classrooms and not feeling comfortable with people there.

Well, every year there was a performance [a Sing]. I did it for a couple of years. Now, I began when I was fifteen to take singing classes. When I was at camp, I always had big roles, depending on my age. The older I got, the more of a lead I had in program[s]. When I was at religious school, I had leads, and when I was in elementary school I would play the lead. But when I was in high school, I'd be in chorus. I don't ever remember auditioning for a part. I was so horrified to even audition for sing, just to be in the chorus.

It had to do with my emotions and my feelings through childhood.

Brown: I was asking how you felt about assistants, getting carried up the steps.

Heumann: Yes. As I said, I just began to realize that it began to become a problem. That's how things kind of formulated themselves, as a problem. It wasn't a problem before; it was a problem now.

Descriptive terminology

Brown: I know you use the term "disabled" to describe yourself now. When you were growing up, how did you think of yourself? What word did you use, or words did you use to describe yourself—either in your own mind or to other people?

[Tape 8-2, Side A]

Heumann: Well, I used the word "handicapped" until the seventies, early seventies. Then in the early seventies I was reading maybe this magazine *Accent on Living*, because my father got that for years. They still get it. My mom still gets it. I read someplace—as I said, maybe there—that people in Scandinavia were using the word "disabled." I thought that was a great idea-this was as I was getting older—in part because disabled people were deciding what they were going to call themselves. It didn't matter if it was "antelope" or "shoehorn" or [chuckling] something. It was an expression of something. There was a whole handicapped—hand in cap, a beggar's term—it was analytical. There were all kinds of things going on, and I thought this is very interesting.

In college I had gotten much more political, over time.

[tape interruption]

Brown: So basically you called yourself "handicapped" until college.

Heumann: But I knew other people who were using the word "cripple." "Cripple" is definitely a word that some people used.

Brown: About themselves?

Heumann: I don't remember that as much as other people calling us cripples, or crippled by. The same old words there: crippled, crippled by—I guess other words—bound to. But I used handicapped.

Concept of inclusiveness

Brown: Who is meant by the term "disabled" I think has changed a lot or at least in theory it has changed, who is included in that terminology. In your early adult years—and by that I mean high school and college—when you used or heard the term "disabled," who did you think of? People with what types of disabilities did you think of as being included in that term?

Heumann: People I knew. Like, when I was in camp I met some blind people and deaf people. I didn't meet them in elementary school or high school. So they were part of that group. People who were mentally retarded were part of that group, because I went to school with people who were mentally retarded, in elementary school. People with spinal cord injuries, because I knew veterans, and people with muscular dystrophy, people I knew. I never felt that one group was not a part of it. I didn't know people at that time who were defined as having emotional disabilities.

But for me it was never a difficult thing to include more people. My concept always was—as I got older and began to get exposed to more and more people—it was clear that we had similar problems. It was who did I feel comfortable with, outside of family and friends. Usually, I'd feel comfortable with anybody I felt had a disability, whether I knew them or not. That wasn't true for nondisabled people. There I had to figure out how to feel comfortable with them.

So that's who.

Brown: Do you think the movement as a whole felt that?

Heumann: It wasn't a movement at that time.

Brown: Well, not movement, but people in the seventies in Sweden—

Heumann: Oh, in the seventies.

Brown: —who were nondisabled. I'm thinking particularly of programs that were called physically disabled students programs, so obviously people were thinking primarily of physical disability. I haven't been clear if people included deaf and blind in that or not. It seems that sometimes they do and sometimes they don't.

Heumann: In Berkeley, they definitely included the blind because they were always, from the beginning, part of things.

Brown: But it seems from what I've read that it has been pretty much wheelchair users and blind people are who were generally thought of to be meant by that term.

Heumann: Well, but when we started our groups in New York City in the seventies, the deaf were involved. I started working with the deaf groups before '75, '73. As I said, for me it was because

I had this experience. I went to this camp where there were three deaf young women in our bunks. I don't know how that happened. There were a couple of blind people there.

In my elementary school and high school, no. There were no deaf people; there were no blind people. As I said, in high school, I don't remember anyone you would define as mentally retarded people. In elementary school, if they had multiple disabilities, then there would be some mentally retarded people there.

As we started getting together in the sixties, kind of organizing, then it was pretty clear that the more the merrier, on a certain level. The discussion that we had was more around how disabled you really were. If you had a less significant disability, you could do more than if you had a more significant disability. It wasn't that you didn't belong, but you could do more.

Awareness of disability hierarchy

Brown: Their issues would be different. A disability hierarchy.

[tape interruption]

Heumann: I think it gets defined sometimes as the disabled community's hierarchy, but the truth of the matter is it's the nondisabled world's hierarchy that we get sucked into, for various reasons. You're more acceptable, I think, to nondisabled people if they can easily understand your language. If they can easily understand your language but you're a quad, you have the problem that you're a quad but they can understand you. But if you have cerebral palsy and you're a quad, then people have difficulty understanding you, and you're a quad. I think we have maybe accepted that because of our interest in being acceptable, but I don't think it's a hierarchy generated by disabled people.

Brown: It's internalized.

Heumann: Yes.

Brown: When you're out in the world and you see somebody you don't know who has an apparent disability, I've noticed that you almost always say hello or stop and talk to them. Is that something that you've always done?

Heumann: As long as I can remember.

Brown: What's that about for you?

Heumann: Just because I feel more of an affinity, and I think it's making eye contact. I'm always curious to see how people respond—not to me as Judy—but sometimes people feel really happy that you said hello to them. They may never think of themselves as a disabled person. There are, like, different reactions. People who are like myself, where you say hello, it's like hi. It's just a nice thing to do. People who you say hello to and ignore you and are not deaf. People who you say hello to who have a disability and are generally excited about the fact that you said hello to them or made eye contact with them. I kind of get this feeling like there's a connection that maybe the person they're with doesn't get at all. But there's just this connection, or non-connection, depending. But there's much more connection than disconnection. I would say out of every hundred people I say hello to, most of them will say hello back. Only a few of them will completely ignore me.

Brown: Do you feel that you have a stronger connection with other people who had polio? Is that true for you? I know for some people it's true for them.

Heumann: I don't know. I mean, I joke about it, but the truth was I didn't know a lot of polios when I was younger. I was the first polio kid in my elementary school. I don't think I really knew polios, really, until I was in camp in high school. In high school there were more polios, at camp. But polios are the best, of course!

Again, it's an area that you understand, so you can talk. I mean, I can't talk to all polios the same way. Most polios had polio when they were younger, so they don't really remember much about it. Then, when you meet a polio who was disabled when they were older, that's very interesting because they can tell you things that you had no idea about.

Brown: Like what?

Heumann: Experiences in the hospital. I heard from someone that there was a lot of crying and screaming that went on because it was painful in the beginning, for some people. I'm sure because kids were away from their families. It was something that happened very quickly, and we were in isolation, and so families couldn't necessarily come and see the kids, for whatever reason. But I definitely joke about polios' being the best, and every opportunity I can, I do it. Because we are. [laughter]

VII. College Experiences: Developing Self-Confidence and Political Awareness; Preparing for Teaching Career

Developing political awareness and activism

[Interview 7: November 11, 1998] [Tape 9, Side A]

Brown: This is an interview with Judith Heumann on November 11, 1998. The interviewer is Susan Brown. We're having the interview in her home on Connecticut Avenue in Washington, D.C.

When and how did your political interests develop?

Heumann: Okay. When and how did my political interests develop? I think my political interests developed over the course of my life. My family was politically knowledgeable, not so much politically active, as in being involved in any kind of political parties, but we read lots of newspapers and magazines and watched the news and always had discussions about things that were going on. It was just part of the environment that I grew up in.

Brown: What newspapers and magazines?

Heumann: *New York Times*, *Daily News*, *New York Post* and other papers that I don't remember because they're since defunct. Just lots of different types of magazines. You know, the more moderate political magazines. So we got *Newsweek* and *Time* magazine and *National Geographic* and *Reader's Digest*, magazines like that. We didn't watch a lot of television when we were growing up. My father and mother read. My father read more of the military-type things. He was always very interested in Second World War, and my brother does a lot of reading in that area.

My political development was also grounded in the fact that my parents were immigrants from Germany, and the impact of growing up in Germany at the end of the First World War—you know, merging into the [Adolf] Hitler regime—definitely influenced my political thinking. My father was very into remembering the past and very critical of the lack of historical knowledge that people have in the United States. His feeling was that history repeats itself, and so one's failure to know what has happened in the past because you believe that it's not going to happen in the future is naive and stupid [chuckling].

I think for myself, I started getting involved in kind of electoral politics of sorts when I was in elementary school—class president in my special ed class—and in high school, for my homeroom I was elected to some position. Then, when I went to college, there was a big change for me because I lived away from home, although it was in Brooklyn.

When I went to college, because it was this transition, it wasn't just going from high school to college; it was, like, really changing environments as a disabled person. It was leaving my family's home where, although I didn't have any personal assistant services or anything like that formally, I had my mother. I didn't have a motorized wheelchair, but I lived in an environment where I could get around in because it was small.

Membership in sorority and political campaign

Heumann: But I was going to college, and the last summer that I was at camp, which was my senior year of college, I met a woman who was a member of a sorority.

Brown: Your senior year of college?

Heumann: My senior year of high school, sorry. My senior year of high school. Who was a member of a sorority, the same sorority that we had on my campus, Delta Phi Epsilon. She encouraged me to go out for the sorority. Now, I was the first in my immediate family to go to college, so I didn't know really what a sorority was. She wrote a letter of support for me, so they rushed me. It was a good thing that I did it, skipping what you think about sororities and fraternities.

What was good for me was that it made me leave my dorm room when I wasn't in classes because there were obligations that I had. As a pledge, I had to go to meetings, I had to sit in the cafeteria and do things for the members of the sorority. So it allowed me to be out and start talking to people and meeting people, even though I was still—this is before I had my motorized wheelchair, and I was much more shy because I couldn't do a lot of things by myself—feeling good about the way I looked and the way I was moving. I always felt different.

The sororities and the fraternities on the campus that I went to ran the student government for the first two years that I was there, although they had run it before, but in my sophomore year I decided I was going to run for junior class secretary. It was in the middle of this transition that was going on on campus between the sororities and fraternities and more of the political activists taking over control of the student government. It was the Vietnam War era, and my college campus was involved in the Vietnam War activities.

Everything for me was new because everything was, like, run by nondisabled people, so any kind of meetings or anything I did I was never just, like, really going there for a political purpose. I couldn't just be there for that. I was always somewhat conscious of

— 121 —

being with all these people I didn't know, and being the only disabled person or maybe one other disabled person.

Anyway, I ran for student government, and I was supported by the sororities and the fraternities. I ran against this woman, Janet somebody. God, I don't why I can't remember her name. She won. She beat me by, like, seven or eight votes. I remember going around and talking to people, "Did you vote? Did you vote?" There were more than seven people that I knew who hadn't voted, so I was very upset [chuckling].

She quit after the first semester of our junior year. She quit the position. She didn't want to do it. I was going in the hospital at that time to get my spinal fusion, but I ran for student government anyway. My friends ran my campaign, the special election, and I won. I participated in all the Student Council meetings through something called an Executone, which is how I went to class. It's from the phone company. It's like an intercom system.

Brown: How you went to your classes in college?

Heumann: When I had my surgery.

Brown: Oh, okay. But generally, when you weren't in the hospital or getting surgery, you went—

Heumann: Yes. So when I ran for student government, friends ran the election for me. I wasn't there. When I served my first term, I wasn't physically in school. I was doing meetings over the Executone. Then people would come to my house for extra meetings. I was involved with a lot of different things: people from the sorority and fraternity, some of the people in the antiwar movement. We also had other activities going on on campus. God, I'm trying to remember when this was. We had a student strike.

Involvement in tuition strike

Brown: The tuition strike?

Heumann: Yes.

Brown: I was going to get into that a little bit more later.

Heumann: Well, it's all part of the political—

Brown: The same stuff. Yes, I understand. Was it regarding tuition increases?

Heumann: Yes.

Brown: Were there other kinds of actions that went on? Were there antiwar demonstrations? Tell me a little bit about what the context was as far as you were concerned.

Heumann: This was '65 to '69. Yes, there were some antiwar activities that were going on.

— 122 —

Brown: What about civil rights stuff?

Heumann: Not a lot that I remember.

Brown: Did people know about it? Were they aware of issues?

Heumann: Oh, sure. People were aware of what was going on in other parts of the country. Now remember, when Dr. [Martin Luther] King [Jr.] was killed and when Bobby [Robert F.] Kennedy was killed, I was at home, recuperating from the surgeries, so I don't exactly know if anything went on on campus. But I don't really recall. The school was mainly a white school. There were minority students there, but at that point it was mainly a white school.

Brown: In terms of antiwar demonstrations?

Heumann: There were antiwar activities going on, but this one particular strike that went on was a very big deal at the campus. There were strikes going on at Columbia [University]. Was there a tuition strike at Columbia also? I can't remember all the details, to be honest. But I remember that LIU [Long Island University] was a less well-known school than Columbia. There were activities going on at our school that preceded activities going on at some of the more prestigious universities, but the other universities have gotten more coverage because they were more well-known schools.

But I was very involved with the strike with the tuition.

Brown: Was it led by the student government?

Heumann: Yes, it was led by the student government, I believe, yes.

Brown: Did you have faculty support?

Heumann: A lot of faculty support.

Brown: So basically just no one went to class, professors didn't have classes? Tell me what happened.

Heumann: There were classes that were canceled. I'm trying to remember if it was my senior year that we had this strike. You know, I can't remember now. I was out of school from January till September. It must have been my junior year. No, it must have been my sophomore year. I'm sorry. I can't remember. We have to look up the year. But I remember that it was a strike that had a lot of support from the cross-section of students at the university, both the students who were left, politically leaning, and the students who were involved in the sorority and fraternity. It was a commuter campus, so a lot of the students weren't necessarily very involved in any of the politics. But it was a very big deal to be having this strike around the tuition.

I guess that was the first time that I was involved in blocking entrances to doors and trying to keep people out of the building. We had a march across the Brooklyn Bridge to City Hall to protest the tuition raise. The Brooklyn Bridge at that time wasn't accessible.

There were lots of people who went on that march. My friends were pushing me, and I would just get lifted up when we got to the stairs.

Participant in political organizations

Heumann: I went to some SDS meetings. They were kind of weird to me. Not the Society for Disability Studies!

Brown: The Students for a Democratic Society.

Heumann: Students for a Democratic Society, right. I could never quite get into the meetings.

Brown: Because?

Heumann: I don't know. Like I said, it was the weirder students on campus who participated in the meetings. I was interested in the discussions. Some of it was a little bit too vitriolic and too dogmatic. I didn't feel comfortable in speaking. It kind of felt more like a cell meeting, where I was being told what I was supposed to be thinking. But anyway, it was a good experience to do it.

Antiwar demonstrations and conflict with father

Heumann: I was involved in some of the antiwar activities. There, I was as a participant. I certainly was involved in letting people know about things that were happening. But it was more as a participant in activities. It was difficult for me to participate in antiwar activities because of my father.

Brown: I was wondering about that. Was he a supporter of the war? Where would you characterize his stand on it?

Heumann: He was a supporter of the United States, and he was very angry with the antiwar movement. He also was angry at the military because he felt that they weren't going in and doing the job the right way. He felt that the criticisms that were going on were hindering the ability of the military to go in and just do what they had to do. So that was a problem.

I remember when I participated in any of the antiwar activities, feeling guilty that I was doing it, that I was somehow betraying my father. On the other hand, feeling like—not that I completely disagreed with everything that he was saying—but that I felt that what was going on was wrong. I didn't feel like I was getting enough information about why we were doing what we were doing, so I was feeling very divided.

I think also the backdrop of what had gone on in the 1930s and my father's continually talking about—and my uncles and others—how people ignored what was happening and were influenced by the wrong side and being influenced the wrong way, so it was a confusing time for me.

I had a pen pal who was a soldier for a while because I thought I had to, for myself, say I didn't have anything against the guys who were in the military because they had no choice, by and large, so why would I be disrespectful of the men? It was the war and the machine of the war that I disapproved of.

So I guess in college what I would say about my politics is that it was the first time that I was really ferreting out for myself what politics was all about, and the different types of politics that there were. There was the college campus student government, the antiwar movement, and then, at the same time, there was my moving through school with an interest in being a teacher, knowing that I probably wasn't going to be able to become a teacher. I would define that as politics also because that's when I started realizing that I had to make some decisions myself about things that I wanted in my life. To start planning for, strategically, what I was going to do if this happened or that happened.

So it was while I was in college, I guess, in my sophomore year that I called the ACLU [American Civil Liberties Union] to tell them that I was interested in becoming a teacher and that I knew of no people who had been hired as teachers who used wheelchairs, and it was my assumption that I wasn't going to get the job because of that. They told me that if a problem occurred, I should call them then, that there wasn't anything to do about it now.

Then I was involved with some people on getting the Disabled Students Program together at Long Island University. I was involved in trying to get the campus more accessible, although not very successfully while I was there.

Establishment of the Disabled Students Program-LIU, 1968-69

Brown: When did the DSP get started?

Heumann: The Disabled Students Program? I would say '68 or '69.

Brown: What happened? Were you a big part of that?

Heumann: God, some of these things I just don't remember well enough. To me, some of these things are just kind of like a stream of things that just happened. Marilyn Saviola and a bunch of us were involved in basically, I think, talking with the administrators there about how we needed to have some kind of a program. Ted [Theodore] Childs was—you could call him if you want to get more—I mean, the two people I would think would be interesting to talk to would be Theodore Childs. He was the first director of the Disabled Students Program.

Brown: He was already at Long Island University?

Heumann: I think so, yes.

Brown: Do you know what he was doing?

Heumann: He was a professor there.

Brown: In what department?

Heumann: Phys Ed. He has been very active in the NAACP [National Association for the Advancement of Colored People]. I think so. He was a physical therapist by training. I can't remember if he was working with the sports people, which might make sense that he was doing some of that. He eventually went on to get his doctorate in special ed. But he was the first director of the Disabled Students Program.

Brown: Was it something that he was instrumental in creating?

Heumann: I think he was involved in it, too. It really started taking off more after I was out of school, but it was being developed while I was in school.

Brown: So was it an actual physical place?

Heumann: Yes.

Brown: Your last year that you were there?

Heumann: I believe it was, yes. I worked there. God, I'm never going to remember all these little time lines. Yes, and had a small staff. He and Gay somebody or other [Harvin]. I think I worked there part-time for a while. One vivid event that I remember with Dr. Childs was that there was an incident where a student was told by one of the professors that he didn't want [the student] in his class because [he] needed a tape recorder, and he didn't want his classes taped because those were his words, and he didn't want them used inappropriately.

Childs said basically, he was a professor on campus, and if he didn't feel comfortable in letting somebody use a tape recorder who had been accepted to the university, then he shouldn't be teaching at the school. I remember that. It was, like, kind of a very powerful thing for me to hear him say that.

Brown: Why was it such a powerful thing?

Heumann: Because he was making his statement, saying that people make choices in their life and you can't discriminate against somebody because you don't want them to have a tape recorder in your classroom. It was a stand against discrimination. He was strong on issues around discrimination, as a black man. At any rate, politically I think all those things were going on for me.

On a certain level, college was like high school for me in my being able to develop in ways that I think high school students were able to do more of. Politics for me also means the ability to be self-expressive and to express a view. Actually, there was a series of events that went on when I was at school. When I was entering my second year of school, there was an incident with the woman in charge of the dormitory who decided that she didn't want me to be there. Did we talk about this already? So you don't need it again.

Brown: Getting back to DSP for a minute, what kinds of services did they provide when you were there? Did you use their services?

Heumann: They helped students with getting classes. It wasn't anything like the program in California. It still isn't. They don't have a wheelchair repair program now; they never did. It was kind of a more traditional program as far as how they went through recruitment and helping do orientation and helping students get books and if they were having problems dealing with those kinds of problems. I assume over time they've got more testing and extended time and things like that, which weren't really an issue at that time.

Brown: So it wasn't attendant services or anything like that?

Heumann: Oh, no, no. I was the only one at the university, that I was aware of, living on campus, who used attendant services. Actually, I think it was Dr. Childs that really got that program going, the Executone program. There were students from Goldwater Memorial Hospital who were coming to school at LIU. It was because of the Executone program.

Weekend at Howard University

Brown: In college, did you study any political theorists or theory?

Heumann: I was reading some of King's work, I think. Yes, you know what? I answered you wrong before. Remember you asked me if there were any civil rights activities that were going on? Yes. I mean, there were different things that were happening that I don't think looked like what was going on in schools in the eighties and the nineties. Things were developing then. But actually, now that I think about it, there were a number of things that were happening.

One is some of us had started an after-school program in the neighborhood. The neighborhood that we lived in was a poor neighborhood, and there had been a lot of criticism by students on the campus that we were kind of a fenced-in school and didn't do any work in the community. So a group of three or four of us—Tony Melli, myself, a couple of other students—started an after-school program, where we worked at the Fort Greene Community Center, doing tutoring and other kinds of mentoring work.

After the riots in D.C., Howard University set up weekend programs. You had to apply and be selected, and you had to read a whole bunch of books: Malcolm X and I don't remember the others. There might have been a King book, an X book. We went down for a weekend, basically to have an intensive on racism. It was at Howard. Lots of discussions in this small group of eight or ten people.

Brown: The eight or ten people were all from Long Island University?

Heumann: I don't remember that.

Brown: But there were about that many from Long Island University? I mean, you said there were a certain number of people that got selected.

Heumann: There were some students from Long Island University. I can't say they were all from Long Island University. I don't remember.

Brown: Was it a regional meeting or people from all over the country? You don't remember.

Heumann: I don't know. All I remember was the weekend and that it was the first time that I had ever been involved in a weekend discussion on racism. I remember we drove through the parts of D.C. that had been burned down. They were talking with us about oppression and how the fires had started and ended, basically still within the confines of the poor neighborhoods. I think all of that was important for me because it just kept expanding my horizon and issues to be looking at and ways to be viewing things, discussions that I hadn't had before.

[Tape 9, Side B]

Heumann: We have Tony Melli. Liked him a lot. I haven't seen him practically since I graduated, but I think we did a lot of our own work on our view of racism and our view of oppression and basic inequities by trying to get involved with the different programs that we set up, that others were setting up. Dr. Childs at that time was beginning to get involved with the TRIO [U.S. Department of Education outreach education grants] program. I think we got a TRIO grant pretty early on.

DSP a Political Entity

Heumann: I left New York in '73. After I left the dorm, I went across the street. The university owned three apartment buildings, and I rented an apartment, so I continued to be involved. I know you want to get into questions about work, but all of this did relate because at some point—I guess, one summer when I was in college—two summers when I was in college, I worked at the William Reed Day Center for Senior Citizens, which was in Bedford-Stuyvesant, I think, in Brooklyn. A lot of my work was really gravitating towards working with minority children and adults. It wasn't possible for me at that point to be working with disabled kids or adults. They weren't kind of like there.

But, on the other hand, I mean, I was friends with disabled students on campus. We were getting involved in lots of different things—the Disabled Students Program and other activities.

Brown: About how many people with disabilities were there on campus? Do you have an estimate?

Heumann: I'd say fifty, but it could have been more.

Brown: What kinds of disabilities?

Heumann: I don't remember there being any deaf students. I don't even remember there being any blind students. Physically disabled students. One of the reasons why I had applied there was because the school was literally on one block. You didn't have to cross the street. So there were students who used wheelchairs, crutches and braces, had mobility disabilities. I'm sure there were students with learning disabilities and things, but there wasn't anything at that time.

— 128 —

Brown: Were you primarily a social group? Did you spend social time together? Did you see yourselves as a political entity at all?

Heumann: Oh, the Disabled Students Program saw itself as a political entity.

Brown: Were most of these people with disabilities involved in the DSP?

Heumann: A number of them were, yes. Linda Slone was another one who was involved. God, I'm trying to remember. Marilyn Saviola. She came to school, and she also was at Goldwater Memorial Hospital. Linda Slone lived in the dorms. She came in after I did.

I was the only disabled person in my sorority. I was the only disabled person on the student government.

Brown: In terms of socializing, did you primarily socialize with other disabled people or not mostly, and could you make any generalizations about them?

Heumann: No, I socialized with disabled and nondisabled people. But socializing was kind of restricted because I didn't have a motorized wheelchair, and I couldn't really get around a lot of places. I had a variety of friends, disabled and nondisabled. I guess it would be fair to say I had more nondisabled friends than I had disabled friends on the university campus, but I also continued to have my friends from off campus, so there I had a number of friends who were disabled, from elementary school.

Brown: In terms of dating, did you date much in college—and mostly disabled, nondisabled?

Heumann: I never dated in college.

Brown: Not at all.

Heumann: Not anybody on the college campus. I never dated anybody in high school. I dated. I didn't date a lot. I still was in camp, when I worked at camp. Was it my first year that I worked at camp? Then my second and third year I worked—that couldn't be right. Yes, it could be. My second and third year I worked at the William Reed Day Center. The fourth year I was out, right? You have three summers: four years, three summers. Yes.

Membership in a disability community

Brown: So in college did you feel you were part of a disability movement or even a disability community?

Heumann: Yes, certainly. Once I was in elementary school, I always felt a part of a movement. Movement is not a word that really applied at that point: group, an affinity. I think those would be more appropriate words at that point. But it evolved into having growing importance.

I guess also when I was in school I was getting involved with going to meetings in the city, '68, '69, I guess. When did I meet Denise McQuade? God, I've known Denise since the sixties. I don't remember where I met her. Not at college, not in high school. I met her.

Brown: What were the meetings you were going to in the city?

Heumann: Paralyzed Veterans of America. [whispering to herself] '69, '70. Some of us were trying to find our place with an organization because we were recognizing that we needed to have our own group. All these charitable groups weren't cutting it, because we didn't identify with them, nor they with us. We were going to some meetings in the city, working on architectural barriers issues. Eastern Paralyzed Veterans Association was doing work on barrier issues.

Brown: This was while you were still in college, with college friends?

Heumann: It could have been my senior year, somewhere. We started DIA [Disabled In Action] in the spring of—

Brown: May of 1970.

Heumann: Okay. You looked that up?

Brown: I have that.

Heumann: Oh, good. Well, then, this was in '69.

Brown: So you were still in school.

Heumann: My lawsuit was in '70 because we started DIA at the same time.

Brown: In the fall of 1970, when you got your license for teaching?

Heumann: I went to California in '73, right.

Brown: How strong was the sense of community among people with disabilities in college? What was your perception of that?

Heumann: The community wasn't big, but the community was important. We felt the bond, I think very similarly to the way I had felt bonds over the course of years when there were problems and issues. It was important to be able to talk to people about feelings of isolation and anger and frustration and the need to resolve problems, so it was important.

I think really, though, for me, in college, while definitely the disabled students were an important part of my life, I think it's for the first time in my life that I can think of more nondisabled people that I knew and was friends with, outside of my neighborhood. I can't really think in high school about nondisabled people who were really my friends, but in college—I think in part because of the dorm—there are lots of people I'd like to see, even if I haven't seen them in thirty years.

Brown: Who were your closest friends in college?

Heumann: Linda Slone was a close friend, Lori Bradshaw; Toni Savage; Angela Thompson, who's dead; Lois Finkelstein, Phil, Eli Frazer, Reva Shulman. Oh, there were other people. College roommates. Mimi Kimmel her name was.

Brown: What kinds of things did you—

Heumann: Tonya. You know, that's funny. We studied, we talked, we'd go to restaurant—Junior's—Tony Melli was the guy I really liked a lot. I said that already. What did we do? Well, nothing was very accessible, so we didn't do a lot of stuff. I don't really think about doing it, even going to the movies, because I went home on the weekends, so a lot of what we did was eat our meals together, talk, do extracurricular activities, work on student government, work on the reading program, work on different things like that.

Oh, went to basketball games. Liked basketball games. Went to a lot of basketball games. Wasn't a formal part of the boosters, but would sit with the boosters. [Albie], the basketball player. I was friends with some of the basketball players. My cousin went to school there the same time I did, Herbie. Some of the guys from Tech. You know, I'm trying to remember if there was a black sorority and fraternity. There might have been, on campus. People came to my parents' home for dinner. Yes, I had a lot of friends. Phil Tygiel, that was his name. And Elaine, his wife. I actually saw them again a couple of years ago.

Brown: When did you become aware of activities of disabled students in other parts of the country? Were you still in college?

Heumann: You know, I can't say exactly when I was hearing about disabled students programs. It probably was when I was in college, reading *Accent [on Living]* or something. But the first ones that I was aware of were Southern Illinois University and University of Missouri at Columbia. There were more formulations of disabled student programs happening in different places: Brooklyn College, NYU [New York University]. I think those are more in the seventies, though. Didn't really start opening up till after college. Then things opened up more.

Attendant services in college

Brown: Tell me a little bit about your attendant services arrangements? Who provided them? Was it usually your actual roommates?

Heumann: The first year I was in school, Toni Savage—who I didn't mention earlier—Toni was my first roommate. She was a friend of Angela Thompson, and Angela Thompson was a friend of mine from before I went to college. She and Toni were in the same sorority, I think. Anyway, Toni was my first attendant. God, I'm trying to remember, she also went to LIU for one year and then she transferred to Barnard, and I think the semester that she helped me out, she might have been attending Barnard and going back and forth between LIU and Barnard.

My roommates were not the only ones who provided me with assistance, because the dorm had a step into it, for the bathroom. I didn't need as much help at that point. But Lois and Ilene helped me out, I recall, and Reva.

Brown: So did you usually have only one person actually working for you at a time?

Heumann: My roommate, yes.

Brown: How many hours a week? Do you have any memory?

Heumann: Well, they helped me up in the morning. I could get myself into bed at night, if I had to, so probably no more than two hours a day.

Brown: Any idea what you paid?

Heumann: No, not a clue.

Brown: So basically they helped you get up in the morning and then go to the bathroom and then maneuvering steps?

Heumann: They didn't help me go to the bathroom during the day. They helped me get up in the morning, get dressed and go to the bathroom, do all that stuff; but they didn't help me go to the bathroom during the day.

Brown: How did you do that?

Heumann: Whoever, whatever.

Brown: So you just found someone you could find to help?

Heumann: Right.

Brown: Were your roommates reliable in terms of helping you get up and the services they did provide?

Heumann: Yes.

Brown: The people you paid were pretty reliable?

Heumann: Yes, pretty much. Yes, pretty much.

Brown: So no attendant catastrophes that you can remember.

Heumann: No. There wasn't very much there in the first place, so it was always trying to work around other people, too.

— 132 —

More on attitudes of nondisabled people

Brown: Did you feel that people treated you differently because of your disability?

Heumann: Yes, sometimes. I had a guy who was on the council with me after we graduated say to me one day that he—it was kind of classic—in the beginning, he didn't think I should have been elected because he didn't think I could do the job. But then, having worked with me, he realized that I could, like anybody else. I remember listening to that and thinking, "God, he's like a book."

Brown: What about professors? Were they ever patronizing or not willing to do what you needed to do? Did you have any resistance, for example, to using the Executone when you needed to do that?

Heumann: No, because the Disabled Students Program was already set up then, as I remember things. Yes, the program was already set up in my junior year. They would have wanted to arrange for people to pick it up and take it to one class and move it to another class. The Executone program was probably one-of-a-kind in the country, and it was great because it really did let the students at Goldwater, who were primarily post-polio, using respirators, go to college.

Brown: You mean unique in terms of going to college? I thought that was how Ed went to high school. You don't remember that story?

Heumann: I thought a teacher came to him.

Brown: I remembered something about him doing something by—it sounded like an intercom system. He didn't use that term.

Heumann: Maybe.

Brown: Were professors ever patronizing because of your disability? Did you have professors who didn't seem to think you could do the work?

Heumann: I—nice music [referring to cuckoo clock]. From our wedding clock.

I don't recall. Nothing stands out.

Brown: What kinds of grades did you get in college? Did you do well in your classes?

Heumann: My cum[ulative average] went up over—I think I graduated with, like, a 3.4 or 3.5. I did reasonably well. I did better in graduate school. For some reason, in graduate school I didn't feel the same kind of fear around tests that I did, but I was always a little overwhelmed in college, trying to do a lot of things. I think I felt much more comfortable than I had on a certain level in high school. But then again, I always had other issues that were going on. Things like how do I get from one place to another because I couldn't push myself, and how was I going to the bathroom. Those are kind of things that were always there.

Trying to be a part of things. That was more the problem. I don't really recall feeling professors treated me inappropriately, but I recall just never fitting in.

I did go with Toni sometimes to Barnard, actually. Then there was another woman that I had met at the camp that I had gone to, Ann Owens. She was a student a Barnard, so I went up to see Ann sometimes, too.

Brown: Besides your wheelchair, did you use any other assistive devices when you were in college?

Heumann: Maybe a picker-upper sometimes. I used crutches and braces until I had my surgery, but I never walked on campus.

Brown: Did you type papers? You've always been able to type fine, right?

Heumann: Yes. You didn't type papers too much. Did some typing, I guess. But stuff was still done manually. We wrote them. I guess my mom typed papers for me. I don't recall having a typewriter in the dorm. I don't recall a typing place. Some students definitely did have typewriters. I had a typewriter that I had gotten from IBM [International Business Machines]. They had a special program if you had a disability. You could get a refurbished typewriter. But I think it was at my mom's.

More on motorized wheelchair

Brown: You talked in earlier interviews about the incredible impact of getting your first power chair. When exactly did you get it? Do you remember when?

Heumann: I think I was out of college. Because I remember being pushed at graduation. It was just a very important time for me because the motorized wheelchair just gave me a mobility that I'd never had before. Again, it's like this developmental delay [chuckling]: on a certain level, experiencing college as high school. The motorized wheelchair is like experiencing—

Brown: College in some ways.

Heumann: No, much earlier than that. No, the motorized wheelchair let me experience being a kid because it was like me first needing to learn how to use it. Then it was learning how to use it meant not just in the apartment but that I could go out, and I could go out by myself, which I had never done in my life. I could go across the street, and I could begin to make independent decisions—if the environment around me—if I could open the door and close the door, and if I could get to the elevator button and all those different things. But it was still, you know, just learning how to do things that people take totally and completely for granted.

I remember having a fight with my roommate and thinking, "This isn't really a fight, that is of a magnitude for how I'm going to respond. But it's the first time that I can leave my apartment and say that I'm angry and leave in a huff." I remember doing that. I was angry about something. I left, slamming the door. I went outside. Now, remember this neighborhood that we lived in was not a very good neighborhood, not one that one should be walking alone at night in.

So here I am, outside, not exactly sure why I was there except that I could be there, and going around the block, saying, "Maybe this isn't the wisest thought." But I remember that was like my first fight. It was great.

Brown: Who paid for the chair?

Heumann: I did.

Brown: The money came from summer jobs?

Heumann: The money came from my work. My father had said—I don't know if they put some money into it—I can't remember that. But definitely some of my money was in it.

Brown: But not Rehab.

Heumann: Not that I remember. I don't think so.

Jobs while a student at Long Island University

Brown: I'd like to move on to some of your jobs that you had while you were in school. What can you remember about your on-campus jobs?

Heumann: You want to do internships and jobs? I had an internship working in the Reading Clinic for part of my requirements for school. Didn't get paid, but it was a job. I had to be there at a certain time and do certain things.

Brown: What did you do at the Reading Clinic?

[Tape 10, Side A]

Heumann: We were assigned children that we worked with, basically around speech pathology issues. Actually, I guess I did one where I had to go do an internship in New York, which is where I worked specifically in speech pathology. At the Reading Clinic, I worked with some young kids on reading issues. Started this after-school program with Tony Melli. We didn't get paid for it, but it was definitely a job because it was a couple of times a week.

Brown: This was at the Fort Greene Community Center?

Job in LIU president's office

Heumann: Yes. I worked at the president's office. I loved that job.

Brown: Was that the receptionist position that you mentioned?

Heumann: Yes.

Brown: How did you get that position?

Heumann: It was work-study.

Brown: So it was just random that you were assigned to it?

Heumann: I don't know that it was random. I can't remember. It might have been that there were jobs you could look for. I don't think you were completely assigned. It was a job I was interested in.

Brown: What did you do, just standard greeting people who came in?

Heumann: I did phones, I did typing. I think I was also on some committee for him then. It was just a way for me to get exposed. The president was Alexander Aldrich at that time. I was on the student government. That's how I might have gotten it, too. I was in student government then.

Brown: Do you have any idea what your on-campus jobs paid?

Heumann: Minimum wage.

Brown: Any concept of what that was?

Heumann: Probably three-something an hour. Geri Costanza. She was one of the women in the office. She was his personal secretary. There was another woman, an African American woman. I can't remember her name. I loved that job.

Brown: Did that lead into the student liaison position that you had? Or it wasn't the same thing?

Heumann: I guess that's what I was doing. That's when I was on some committees and things like that. Oh, that's what it was called, yes.

Brown: Did you get to meet with the president regularly?

Heumann: Oh, yes. I mean, it wasn't a huge—there were two outer offices and his office, so you saw him all the time. I remember there was a bomb threat on campus, and the FBI [Federal Bureau of Investigation] came. That was a riot. It's funny you remember certain things like as if it was yesterday? These three guys come in in trenchcoats. I'm, like, this is so classic! This is really the FBI. They look like what you expect the FBI to look like.

Brown: This was while you were working in the president's office?

Heumann: Yes. No, it was a nice office. Again, those were good experiences for me because I was learning and I was able to come into myself a little bit more. Disability was always something that I was interested in and pushing, at the same time that I was also just being able to develop my skills. Not that I was going to be a secretary, but it was like information, which is why I really like doing those kinds of jobs because you knew all the calls that were coming in. That was good. That was a good job.

I worked at the Disabled Students Program, again, kind of receptionist kinds of things.

I graduated in '69. I worked for the Alumni Association.

Brown: Why don't we hold off on when you graduated and just finish up college.

Heumann: I think those were my jobs in college.

Brown: So during college breaks, did you mostly—

Heumann: I'm sorry. During college breaks—

Brown: What did you do?

Heumann: One summer I had this, yes, I think I had said this already. One summer, the first summer I worked at the camp.

Brown: Camp Jened.

Senior citizen center

Heumann: The next two summers I worked at the William Reed Day Center for Senior Citizens. There I was kind of like a social worker.

Brown: Was that a drop-in center, a community center?

Heumann: It was a senior center. It was actually in a building that was a residential building for seniors, in a housing project, in a low-income housing project, which was basically black. There I ran programs, I did intakes. I was a social worker, basically. Also made friends with kids in the neighborhood. There was this one family. They had, like, sixteen kids. My mom would drive me every day and pick me up, and I remember becoming friends with Joey and his brothers and sisters. Actually, I think they came to our house once, a picnic or barbecue or something.

I was always the networker because I was friends with the younger kids. I wanted them to come up to the senior center. Some of the seniors wanted nothing to do with the younger kids, and some of the seniors did. So I was always trying to figure out how we could get the seniors to recognize that if they were feeling vulnerable in the community (which was what was going on), they needed to have allies. To the extent that they didn't want to deal

with the kids, that was a problem because then the kids didn't feel connected to them. That was two summers.

Then I graduated and did the Alumni Association work.

Graduation from Long Island University

Brown: What was graduation like?

Heumann: Oh, you know, not great [chuckling]. I had fallen and sprained my knee and my ankle. I didn't like when I didn't have a motorized wheelchair because I was so dependent on people. You know, marching down the aisle and doing all this stuff. I don't remember who the college speaker was. I mean, it was fine. Not a momentous occasion in my life. Not like high school graduation, which was a real bummer.

I remember feeling sad about the fact that I was maybe not going to see some of my friends because there were people that I really liked. But the graduation itself, in spite of my sprained knee and ankle—

Brown: It was at least accessible?

Heumann: It was outside, on the lawn, yes.

Challenges in college

Brown: What would you say were your greatest challenges in college?

Heumann: Balancing all these things, knowing that you're there to study, but also trying to develop myself and having these restrictions. So it was like being able to be doing more than I was able to do before, but not that much more. Again, it was a contained environment, the floor of the dorm. Freshman and sophomore year we lived in rooms; junior and senior year we lived in apartments. I liked the rooms a little bit more because they opened up onto a floor of other rooms. The apartments were already more restricted, you know?

But college—unlike high school where I feel like I kind of held my breath—college at least feels like I began to breathe. In spite of the fact that there—I mean, obviously, the thing of not dating—was always an issue because I just never felt completely the same. I think the other thing about college was that other people were thinking about employment, and that was a real uncertainty for me. So on the one hand, I was studying to be a speech pathologist, knowing that I didn't want to be one.

I guess the other thing that was going on while I was in school is that I was continuing to study voice. My father took me to the city at least once a week, for me to study voice—or my brother. That was something that I was toying around with. People said I had a good voice; I should do more with it.

I was involved in a volunteer hospital group where we would do performances.

Brown: Was that with Cyrus Abbey?

Heumann: Yes. Was that after '69 now?

Brown: I think it might have been after college. I'm not sure when you actually got involved.

Heumann: Right. How did you know that?

Brown: An article.

Heumann: Yes. So that was going on. Then I was having to prepare for taking the teaching exams.

Brown: You were studying for those already your last year of school?

Heumann: We didn't study for that. At that time, you only needed twelve credits, and then there were these three requirements: the medical, the oral, and the physical. No, the medical, the written, and the oral.

Brown: But you didn't study for the written and the oral tests?

Heumann: No. I never knew there was anything you could study from. It was just basically you went and took the test. So I did. But that was after college. Again, no one was really talking to me about career. People thought I was going to be a speech pathologist, although Childs knew that I wanted to be a teacher.

Regrets about college experience

Brown: Do you have any regrets?

Heumann: Of what?

Brown: Of college?

Heumann: Regrets. [pausing a long time] I mean, it would have been good if college would have been more normal for me, like for other students. You know, had I had a motorized wheelchair, I think it would have been a big difference. Had the city been more accessible, it would have made a big difference. So I regret, yet again, not having a more, quote-unquote, "normal" time, normal developmental period.

Sometimes I regret not studying hard enough. Not taking different classes. But basically, no, not a lot.

Brown: Anything else you want to say about college before we move on?

Heumann: Well, it was interesting that when I was in college no one ever understood why I was taking the classes I was in teaching. I think one of the other things that did happen in college was because I was so active in the strike and other activities that I did have a level of respect and recognition from teachers on campus who were of that persuasion [chuckling]. That was good. I think it also was an opportunity for me, as I've been saying, to begin to do work in a more integrated setting, although it was still confined.

I liked a number of my classes. I liked good exchanges with the professors. I never felt completely comfortable with my writing. Papers were always difficult for me because I never felt like I got the right instruction in how to write papers.

I guess one thing that changed for me was before I had my surgery, I used to be able to read in bed. I could lay on my stomach and work in bed and read in bed. Once I had my surgery, my spinal surgery, I couldn't do that anymore.

Going to school from January till August, through the Executone, was a very interesting experience because it really paralleled more home instruction—although I was in class but I wasn't. I could speak if I clicked. My grades were better then. It was kind of like when I wasn't in the middle of the competition, my grades were better.

Brown: But wouldn't you also have had more time to study because you weren't doing so many more social or political activities.

Heumann: Yes. On the one hand, that's true; on the other hand, it wasn't, because I had a lot of company all the time. I slept in my parents' dining room, so my mother was home all the time, so she was there; her friends were coming and going, so I had less privacy. I did on the one hand have more concentrated time for studying, but I don't think that was it.

I think one of the reasons graduate school was easier for me was because the classes were smaller. The bigger the classes, I just have more of a problem. The smaller the classes, the more intimate it feels. The more intimate it feels, the less competitive it feels.

Brown: So was it competition? Or did you feel intimidated by the professors? I mean, what about the smaller setting made it easier for you?

Heumann: It was more normal, more casual. To me, I think of competitiveness, grades—the bigger the group, the more you have to be—every time you open your mouth you have to make clear your points more than if it's in a smaller group, when it's more dialogue.

Brown: You're speaking in the present tense now. Is that something that still holds true for you?

Heumann: No. No, it definitely was from then that I'm speaking of, not using the right tense. But it was curious that when I did this, it was basically three semesters because I did two summer school semesters and a full semester, and I did better and I felt better and I think in my senior year I did better. It could also be just that I was—

Brown: Become more accustomed—

Heumann: Right, that could be true, right.

Brown: Any last thoughts on college before we move on?

Participates in play

Heumann: I was in a play. Did we talk about that?

Brown: What play?

Heumann: Oh, my goodness gracious. [pausing for quite a while] [Eugene] O'Neill? [whispering] I can't remember the name.

Brown: So now you're going to recite all your lines for me.

Heumann: No. I played an old woman. It was very funny. When I came to audition, Dr. Edwards was the teacher. Eugene O'Neill was the playwright. I came, of course, in my wheelchair. She was thrilled because there was a part for an old lady in a wheelchair, so guess what I was: the old lady in the wheelchair. When the newspaper did the review, they said I didn't seem like an old lady; I seemed too young. I was nineteen or something. Yes, I guess I'm not seventy, and I didn't act seventy. That I definitely remember feeling like I was glad that I was doing it.

I didn't have a lot of lines. But I was not happy about the fact that I was never sure would they have given me this part had I not shown up in a wheelchair [laughing]? I used an old wheelchair for the part, a wicker chair.

But, on the other hand, it felt much more comfortable to me than when I was in high school. We did those high school things. Those felt large, and I felt very invisible. Here, while I felt stupid [chuckling], I felt more a part of the group because it was smaller, a small cast.

I loved working in the after-school program. It was a great experience for me.

Brown: What did you love about it?

Heumann: I loved working with the children and I just liked being with the kids. It was good. I liked being with the kids because I also felt like I was helping them learn. But for me, I was also learning. I really enjoyed that experience a lot.

More on college jobs

Brown: What did you do the first summer after graduation?

Heumann: I'm not sure. I did some work at the Alumni Association. I know it's not on my résumé. Maybe I thought it was so irrelevant I skipped it! But I think I was doing some minimal work. I got paid for it.

Then, in the fall, I was working for the university on this issue of whether or not the university was going to be purchasing a building in the community.

Brown: What was the purpose of that building? Was that sort of an extension of your after-school community involvement?

Heumann: You know, I have to say I can't talk a lot about this. It's weird. But it was definitely an extension of—what we had been trying to do was to make the university go beyond—you know, it's a small little area—and reach out into the community. The first summer I could have also worked for the Disabled Students Program. I could have done that. [whispering] I don't remember. I have to think about this.

One year, actually, as I think about it, I worked at a hospital in the neighborhood.

Brown: After college, or during college?

Social work at Cumberland Hospital

Heumann: I don't remember when, but I definitely worked at this Cumberland Hospital.

Brown: What were you doing?

Heumann: Intakes. Basic social work. I don't remember for how long or when, but I do remember it because I had a guy come up to me once and tell me—talked to me in Spanish—couldn't answer him. Said, "I'm sorry, I don't speak Spanish." He got very upset because he told me I couldn't speak Spanish. He was clearly Puerto Rican, and I wasn't speaking to him in his language. I was very apologetic and said—that happened to me once before. I told him I was very sorry. I didn't speak Spanish but couldn't even say I didn't speak it in Spanish [chuckling].

Brown: How long was—

Heumann: I don't remember. I feel badly. I don't remember these things.

Brown: What about some of these other positions?

Remedial reading program

Heumann: I did adult ed. That was evening. My friend, Toni, ran the program. I taught vocabulary and it might have been what we call today English as a Second Language, but I definitely remember teaching a vocabulary course. I taught two semesters, yes. But that was in the evening.

Brown: What about a remedial reading program?

Heumann: That was the Board of Education in New York—

Brown: New York State?

Heumann: City. Wait. Which one are you talking about? Yes. No, New York State. They had a program that was really for black young men. They called them students with CRMD, Children with Retarded Mental Development. There were kids that came to my house, and I tutored them. Basically, they were second-, third-, fourth-grade reading level kids who weren't being served right.

Brown: They were age sixteen to twenty-five?

Heumann: Whatever, yes. Yes, that was before New York was doing even a worse job than it's doing today [chuckling].

Brown: The remedial reading program was part-time? The adult ed instructor was an evening position?

Heumann: They were both part-time.

Brown: Okay. Was this also part-time, the research assistant?

Heumann: No, that was during the day. I don't remember whether it was full-time or part-time, but I know that the reading program and the—yes, so from '69 to '70, I did work for the university; from '69 to '70, I did the remedial reading, which was part-time.

Brown: Did you enjoy those jobs?

Heumann: Yes, both of them were fine. I liked working with the kids. I always liked working with kids and I at least was trying to do something for kids who clearly hadn't gotten what they needed. They weren't bad kids. They clearly came to my house. They didn't have to come, so they wanted to be learning. It's very unfortunate.

Upward Bound program

Heumann: Then the Upward Bound program, which was in July and August of '70. I really liked that program. That was junior high school students.

Brown: What were you doing with them?

Heumann: Tutoring and counseling and just working with them. It was out of the Disabled Students Program.

Brown: So those were disabled students?

Heumann: No, it was run at—Dr. Childs was expanding the program. I can't remember if the name of the program had already been changed, but he was the one who had organized it. It was a TRIO grant, I believe. I became good friends with some of the kids. One of the articles that was written after I had gotten my job, *Good Housekeeping*, had a couple of those students in the article; they were brothers.

Brown: What about working at the Fort Greene Community tutorial program in the summer?

Heumann: It's just a volunteer program that we got money for that summer [chuckling].

Brown: So that was a paid job.

Heumann: Yes. That's what it says [laughing].

Brown: The résumé must be right.

Heumann: Right. Didn't lie on the résumé. Just don't remember it now.

Brown: We need to wrap up soon. Is there anything else you want to say about any of these jobs?

Heumann: These jobs were important jobs for me because this was when I was definitely moving forward to get my teaching position. What I had been trying to do in my last couple of years of school and during this time period was to get myself more teaching experience because I had none. So it was all me teaching myself how to do these things, which of course isn't the best thing, except that it at least allowed me to develop rapport with students, even though I taught young kids and my experience really was with junior high school and high school and above—college kids, and adults in adult ed. At least it let me know that I liked to teach.

They were good jobs. I particularly remember the teaching ones as being enjoyable. Most of the kids that I worked with were minority kids. There were some disabled students in the Upward Bound program, but there were also a number of minority kids who were at risk, which is why they were in the program.

VIII. Preparation for Teaching; Denial of Teacher Certification and Lawsuit; Teaching Experiences in P.S. 219

Preparing to teach and get teacher's credential

[Interview 8: January 30, 1999] [Tape 11, Side A]

Brown: We're going to start with your struggle to get your teacher's license. Go ahead and just tell me about that.

Heumann: Okay. I guess when I was in high school I thought, when I began to think about careers, which no one really focused on with me, I thought about teaching because I like children. I actually was interested in a theater career, but that was something that seemed pretty unattainable, and my parents were definitely focused on my pursuing a traditional career. Did we talk about my applying to Julliard?

Brown: Yes.

Heumann: So when I went to college, I had been told by friends that I should—didn't we talk about this, too?

Brown: Yes.

Heumann: Okay. Where do you want me to go?

Brown: I guess just start at after you finished college. Actually, I would be interested in knowing how you found out what the process was, because it's my understanding that you didn't really tell anybody that you wanted to be a teacher—anyone official—because you felt that they wouldn't pay for you to do that. So kind of how you led into that and then taking the exams and what happened from there.

Heumann: Well, you know, at any university, you major and minor. In the 1960s, during the baby boom era, there were too few teachers, so they began to bring teachers in that didn't have

— 146 —

to have as many credits as they previously had to have. That was kind of a stroke of luck. Did we talk about the ACLU [American Civil Liberties Union] stuff, too?

Brown: No. I was hoping we would get to that.

Heumann: Okay. So friends of mine had told me that if you go to the Department of Rehabilitation, you can't ask to major in anything where you can't also say so-and-so, who has such-and-such a disability which was similar to mine, has the kind of job that I'm interested in getting. So just tell anyone that I'm majoring in a traditional field. I think we talked about going to Rehab and my experiences.

Brown: I think so. Would you like to talk about it a little bit more?

Heumann: It's just that when I went to Rehab, I definitely didn't talk to them about being a teacher, but did talk to them about wanting to be a speech therapist.

Brown: Right. So you were pushing that aspect of it, because you knew people that were speech therapists that had similar disabilities.

Heumann: Exactly. They gave me this battery of tests which said I should be a social worker. That's what they told me that I should be. My parents just said, "Look, she wants to be a speech therapist. Let her be a speech therapist." So they did. When I went to college, I majored in speech and theater, and I minored in education, which meant I needed twelve credits for a minor. In the sixties, as I said, you didn't need to have a full credential in education. I took four courses and, at the same time, I also was trying to create opportunities so I could get some teaching experience.

Brown: I know you did a number of tutoring jobs.

Begins process to get teacher credential

Heumann: So I took my courses, and then, when I graduated, applied for a teacher credential at the Board of Education. They tell you what you had to do. I had to take a written exam and an oral exam and a medical exam.

Brown: The written and oral—did you take those right after college?

Heumann: You take it all after college.

Brown: But I mean right afterwards?

Heumann: Let's see. I graduated in '69. I took it in—yes—I can't remember if I took them in the fall of '69 or '70, but I took it.

Brown: Did you have to study for it or was it that kind of a test, or it was just that basically you should just know?

Heumann: I just took the test.

Brown: It wasn't like an SAT [Scholastic Aptitude Test], where you can take practice exams?

Heumann: I don't know. Maybe. But I didn't.

Brown: You didn't. Okay.

Heumann: Because I wasn't majoring in it. But I mean I passed all the tests. There was a written test and an oral test. I passed the tests. I didn't have a clue what was going to be on any of the tests; I just [chuckling] did them, which actually is interesting, given my phobia on tests. But all three of the exams were offered in inaccessible facilities, so I had friends who carried me up the stairs for the written exam and the oral exam and the medical exam.

Do you want me to talk about the exams?

Brown: Sure.

Heumann: Well, the written exam was uneventful, except that I had to get carried into it. The oral exam, I remember, no one said anything to me about my wheelchair, but because it was in an inaccessible building, I couldn't use my motorized wheelchair, so it was, like, I had to be pushed in. I remember feeling like they were really looking at me, the evaluation team. But nonetheless, I passed it.

Brown: Were the evaluation team just teachers, principals? Do you know who they were?

Heumann: I have no idea.

Brown: Just people sitting there.

Heumann: You go in there, you take the test—whoever. I have no idea.

Brown: Wait for your results.

Heumann: It actually really is interesting, because I was always so nervous about tests. But I don't remember being nervous about this.

Brown: Were you nervous about oral tests, too, or did you not have any of those that you could judge?

Heumann: I didn't have oral tests. But I wasn't nervous, really. I was a little nervous about the written exam, especially since it was going into the unknown. When I think about it, I was surprisingly un-nervous about it. So those were uneventful, except for the sense that these people kind of were looking at me a little strange[ly], but they didn't fail me on the test.

— 148 —

Experience of medical exam

Heumann: Then I took the medical exam, where I had an old woman as the doctor. She was just not into it from the very beginning. It was almost like she was a little bit, I don't know. It was very strange. The types of questions. She didn't follow, like, the format because I know that she didn't ask everyone she evaluated to show her how they went to the bathroom, which she did. First, I remember being completely blown away by the question. Then I remember saying to her that I could assure her that if my job was to teach children how to go to the bathroom, I'd be able to do that.

Brown: [chuckling]

Heumann: Then, in taking my medical history, she found out that I used to use crutches and braces. I told her I didn't use them anymore because it was after my spinal fusion, and she said I had to bring them in. I had to come back for a second medical exam and I had to bring them in and I had to wear my braces because I had to show her how I walked. I remember explaining to her that I would never be safe in a classroom as an instructor using my crutches and braces because I couldn't stand up by myself, I couldn't sit up by myself, it took me a very long time to walk, and I was completely unstable, so it wouldn't be appropriate for me to be teaching using them. But she insisted on it.

So we came back for another medical exam. This time I brought the director of the Disabled Students Program at Long Island University, Theodore Childs. He's an African American man and was very active in the NAACP. I said, okay, I'll bring him and he'll come into the interview with me, and at least I won't feel so vulnerable, like I did the first time. But they wouldn't let him in. They made him wait outside. This time she had two other doctors with her. I didn't bring in my crutches and my braces, and so they wrote down—I remember reading upside down on the form—that I was insubordinate.

At one point, this doctor—the woman—said to these other two men, "She wets her pants sometimes." I remember sitting there, thinking this is not really happening. It was like she had this fixation on bathrooms because the previous time she had asked me to show her how I went to the bathroom. I'm like, I really am not hearing this. I said, "What are you talking about?" But the truth is I was ready to cry throughout this whole thing because I was only twenty-one or twenty-two years old. I was trying to get a teaching credential, and I knew there were going to be problems with it, but the truth of the matter [is] you can't really prepare. Had I been trained by the best of people, which of course I hadn't been, no one would have said to me, "Be prepared for personal, invasive questions."

Anyway, I left that interview not with a very big sense of this is going to be a positive result. I guess it was in February, I graduated in '69, and I started teaching in February of '70.

Brown: You got your license in June of '70.

Heumann: Right, but I got my notification of denial in February, so I did take the test, by the way, right after school because I graduated in June. So by February I had been denied the job.

Brown: Were you expecting that? Did you get a piece of paper in the mail that said you failed, and you were expecting that?

Heumann: I wasn't expecting to be passed, ever. Because when I had called the ACLU in my second year of school, it was totally expecting that I wouldn't get the job because I didn't know anybody who had been teaching in a wheelchair. I figured out of 70,000 people, it's not that I knew the 70,000 people, but I would talk to people—nobody knew anybody who was teaching in a wheelchair. I did find out later that there were a few people that were, people who had gotten their credentials prior to having their disability and had MS [multiple sclerosis] or something like that, but no one with it.

So I wasn't—you know, you could expect something and then it happens, and it's not that you're surprised by it, but it still hurts you.

Brown: Sure.

Heumann: So I remember when I got it and it said I had been denied my license, I think I called or wrote back to ask why. They then sent the letter which said that paralysis of both lower extremities, sequela, poliomyelitis—

Events leading to lawsuit

Heumann: So after I got the official letter of rejection, then I had to start figuring out what I was going to do. I remember I talked to my parents, talked to my friends, and was trying to decide what to do and how to do it. Things just kind of fell into place because there was a guy named—I think his name was Sam—a disabled guy, who was a journalism major in school. He worked as a stringer for *The New York Times*. I talked to him, and he got a writer named Malcolm. Do you have the article there?

Brown: No, not about that. Those are all still at my house.

Heumann: Okay. We can look up his name. Anyway, he wrote an article on a Wednesday about my being denied the teaching credential. Then the next day, on a Thursday, there was an editorial in *The*

New York Times supporting my getting a job. That same day, that Thursday, I also got a call from a man named Roy Lucas, who was working with an organization, a small organization that was doing constitutional law work. He was writing a book and had read the article in the paper, and so called to talk to me about what was happening. While he was interviewing me for the book, I was interviewing him. At the end of it, I asked him if he would be willing to represent me, and he said he would.

Then, the next day, we got another attorney, Mr. [Schwartzbart], who was a customer of my parents. Then, on Thursday, I got a call from NBC, the "Today Show," asking me if I would come on. They set up a debate between me and a guy named Bob Herman, who was, like, the deputy—I don't know what his title was—but he worked for the Office of Special Ed in D.C.

Brown: Like what you're in charge of now?

Heumann: What at that time was the equivalent.

Brown: Oh, from Office of Special Ed Programs. So this guy was debating—he was basically—you were pro, you should get your license; and he was con?

Heumann: He wasn't really con, but they kind of set it up as a debate. He was a nice guy, but I didn't know him from a hole in the wall, and so I just basically was ready for—what is it? A dog all revved up for the rabbit? What do they say?

Brown: I don't know.

Heumann: It was some saying. Anyway, I was all revved up. I was whatever it is. Then a number of things happened. I don't remember the dates that we finally filed. I'm sure that Roy called the Board of Ed and was told that yes, this is why I hadn't gotten the license, or that it was true. We went to court and got a date.

But at the same time that was going on, there were all these other things happening in the media, because once *The New York Times* did an editorial, then the *Daily News* did an editorial, and the *New York Post* did an editorial. Actually, there were all these letters that were being written. Some congressional women in Washington were writing letters to City Hall—I don't know who they were—basically saying, why isn't she getting a job?

Wins in court

Heumann: We went to court. Had a woman named Constance Baker Motley, who was the first African American woman judge in a federal district. I guess they change benches. I don't exactly know how it goes, but she was making a change in her assignments, and she told the Board of Ed that she fully intended on keeping this case, and so she encouraged them to revisit it. They did, and I went down for another medical exam, which was completely inconsequential. A younger woman sat at her desk, had some forms, said, "I'm sorry. This never should have happened." I got my license.

Brown: You did actually sue them, but did the suit ever go to court?

Heumann: Yes, we went to court.

Brown: So why did you have to have the medical exam?

Heumann: Because the court ordered it.

Brown: Oh, okay, a real medical exam.

Heumann: No. The judge said, "I'm not letting this case go. I suggest that you do what you need to do to resolve the problem," which was that I had failed the medical exam, so they gave me another medical exam. But it was nothing. I mean, it was less than a doctor's visit. So then, when I got my teaching credential, I couldn't find a job because there weren't any

principals that wanted to hire me. Again, I had not yet exhausted the world of principals, but—

Hunting for a teaching job

Brown: But wasn't it also partly an issue of the timing of when you got your license, and so it was June and the jobs were available in September, that there wasn't necessarily a lot of time—I mean, wouldn't a lot of principals already have filled a lot of slots? That's one of the things I read in one of the articles.

Heumann: Is that what it said?

Brown: Something that a lot of people said, "Well, I would have given you this job a few months ago, if you had come when you should have had you not failed the medical exam, and I would have had a job for you then, but given that there's such short time, I couldn't keep the position open for you."

Heumann: It didn't feel like that was an honest answer. In fact, teachers do leave at the end of school years, who didn't necessarily give notice that they were leaving. But nonetheless, the principal of the school I had been a student in offered me a job, so that's where I went to teach.

Brown: Going back a little bit, at what point did you decide you wanted to sue the board?

Heumann: It was something that I had obviously been thinking about since I was in school in my second year. I think I made the final decision the day that I found a lawyer. One of the obvious barriers in trying to decide whether I was going to sue the Board of Ed was finding a lawyer. It's not like today, where you've got disability rights programs that you can just call and say, "Oh, by the way, I've just been discriminated against. Have a lawyer for me." There was no such thing as have a lawyer.

I had a cousin who was a lawyer. I don't know if I ever spoke to him. I don't remember. But I didn't really know any lawyers. So it just all was meant to be because somebody calling me that I didn't even know, who could represent me well.

Brown: I also understand, obviously—from the things that I've read and from things that you've said and things your mother said in the interview with her—that public opinion was absolutely behind you, pretty much all the way. Was there anybody on the other side, saying, "Well, she shouldn't be a teacher, and here's why," or was it just a matter of the Board of Ed digging in their heels and saying, "Well, that's just what we've decided"?

Heumann: You know, in something like that you don't really know who's saying what. There were, I think, a few letters or something that were kind of in the paper, although I'm not 100 percent sure, that were somewhat questioning. But as a rule, opinion was very high for my getting a license and teaching, because of the shortage and because people felt that I would be a great role model for kids. Yes, the Board of Ed is a bureaucracy, and there are rules.

— 152 —

There had been a law passed in the forties, I think, under [then-Mayor Fiorello] La Guardia, which had basically said disabled people couldn't work if you had certain types of disabilities, so the history was there, yes. I think I may have spoken to some people on the phone who didn't feel good about it. Had I not gone to court, I wouldn't have got my teaching license. Bottom line.

Contacts ACLU and gets rejected

Brown: Now, when was it that you called the ACLU? Did you call the ACLU when you were thinking about suing? Did you call and ask for their support?

Heumann: I called in my sophomore year and said, "I'm interested in being a teacher. I'm about to start taking classes. What should I do?" They said, "Don't worry. If you have a problem, call us and we'll talk to you then." So after I was denied the teaching license, I called them again and explained that I had previously called them and explained what the situation was and that I wanted to come in to talk with them. They didn't want me to come in and talk to them. Give them the information, send them whatever there was, which I did. Then they contacted me and said that it wasn't a case of discrimination because they had denied me on medical reasons, on medical grounds.

I said, "Let me please come in and talk with you and explain to you how denying me my job on the grounds of medical condition is in fact discriminatory, and you can't write it off as I failed the medical exam." But they wouldn't set up an appointment for me to come in and talk to them.

Brown: How did you feel about that?

Heumann: I was very angry. I didn't know anything about the ACLU, really, at that point. Of course, now I know more about them. I had a problem with them later on. I was at CIL, so this was in the seventies. My friend's father had nominated me for the board of the ACLU. When I told them that they'd have to pay for an attendant, they called me back and said they didn't pay for childcare, so they wouldn't pay for an attendant.

Brown: This was in the seventies?

Heumann: Yes. I explained to them again that, whether or not they should pay for childcare wasn't the issue, although clearly it might be something to consider if they were looking for somebody who couldn't be on a board. But in the case of disability, it clearly wasn't the same as childcare. They wouldn't do it.

Brown: Do they have any more of a clue now?

Heumann: I don't know. Mary Lou [Breslin] was on the board locally for ACLU. I don't know of anybody who's on their national board who has a disability.

Brown: Did you get damages from your suit?

— 153 —

Heumann: No, no, I didn't get any money.

Brown: But you did sue for damages, seventy-five thousand dollars.

Heumann: Yes. We didn't get anything.

Brown: For hardship.

Heumann: Once I got the license—

Brown: That was all you really wanted.

Heumann: Yes. Once I got the license and the job, we dropped everything. Silly. Probably shouldn't have. But that's history.

More on lawsuit

Brown: Actually, that's one of the questions that I was going ask in a minute, but I'll go ahead and ask it now. From the vantage point of these many years later, is there anything you would have done differently in that fight?

Heumann: No, not really. I won [chuckling]. I got much more publicity than anybody ever thought. We didn't plan any of it. There were articles—between newspapers articles, magazine articles, radio and TV interviews—there was something at least, even towards the end of the year—something at least once a month. So over the course of a year, there were some weeks where there were all types of newspapers articles and TV or radio interviews going on.

So no, I think now, looking at the issue of letting the $75,000 go, it would have been better to try to do something and stick it to them. Then I was getting ready to start teaching, so there wasn't time for that.

Brown: Right. So did people stop you on the street?

Heumann: During the whole thing, during that whole year, it was pretty amazing the number of people who stopped me on the street. People would be in their car, driving down the street, honk their horns for me to go over and say hello. People would stop me in stores and on the street. Some of them would just say, "Congratulations. Keep it up." But there were others who talked about people they knew who had disabilities who were having problems of discrimination.

I and some of my friends had decided, when it was apparent that we were getting a lot of publicity out of this, to not just talk about the discrimination against me in my looking for a job. We decided that we would really focus it on the kinds of discrimination that disabled people face, which also made it a more interesting story, I think.

Brown: It seems like it was obviously a pivotal point in your life, winning your license. How do you think that has affected the course of your life since then, particularly in those earlier years?

Heumann: I think it was just another step, so to speak, in my life because it was a major hurdle. There's no doubt about that. It was a very publicly displayed issue. But it still was just something in the continuum. It sticks out as obviously an important part of my life, but it doesn't feel that it takes a higher place than some other things. I think it helped me with my resolve that if you stick to something you can really win. Not to give up and to kind of pursue it any way you can.

Brown: Did it have much of an impact on how you felt about yourself?

Heumann: Yes, I do say in speeches that I think if I hadn't done it, it would have had a very negative effect on myself. I really had to make a decision that not only would I go ahead with the lawsuit, but in going ahead with the lawsuit it meant that—

[Tape 11, Side B]

Heumann: I think had I not gone ahead with the lawsuit, it would have been a big problem because I would have basically never known whether I was able to teach. It would have meant that I was accepting what the system was saying to me and to other people. So, by going forward with this one, even if I had lost, at least I would have been fighting for what I believed in. But the fact that I won just really reinforced to me that there were a lot of issues of discrimination that we were facing, and if we in fact pursued a remedy, that we could get them, in many cases.

Brown: Is there anything else you want to say about the lawsuit?

Heumann: The lawsuit itself?

Brown: Any of it.

Press and TV interviews

Heumann: I remember the day of being in court. It was kind of awesome. Here I am in this court, with this judge. It did feel like I was fine because for some reason, when I think back about the judge on the bench, it does feel kind of godlike. She was kind of all-consuming in the room. Of course, she wasn't, but I just remember that, sitting there and thinking, "Wow, this is pretty amazing, that this is happening." It didn't take very long. But everything felt very serendipitous: the newspaper articles, getting an African American woman as the judge. The symbolisms were very powerful for me.

Once the interviews started, I had never done that before. I had no public speaking training or classes to take about how to present yourself to the media. It was, like, get a call on a Wednesday, do an interview for a newspaper, have an editorial, and then get a call to go do the "Today Show." It was, like, Well, do the best you can do. I really got into it [chuckling].

I remember thinking it was good, what I had learned from my father. Really, our dining room discussions were definitely preparing me for debates and definitely prepared me not to be a quiet, unassuming person but, rather, to be a New Yorker and go for it and interrupt and do whatever you needed to do to get your point across.

After I did this interview with Bob Herman—who I didn't know from a hole in the wall—when I met him years later because of other work I was doing—he kind of characterized it as, he supported my position, but he had to get out there and not oppose my position but debate it. He was a Jewish guy also, from New York, so it was kind of funny, really. We did laugh about it a number of times.

But it was very good. It really allowed me to realize that I had different qualities that I could use. I mean, I knew I had the ability to speak before, but I didn't know that I could do television. So that was all very good.

Brown: Were you nervous about speaking to the press or being on TV?

Heumann: I think I probably was nervous. You're always nervous a little bit, but I guess the other thing for me is I had studied voice for so many years, and I had done performances, and I've been through my nervousness, where I would cry on stage at the synagogue or when I did my bat mitzvah—oh, gosh! When I did my bat mitzvah—did we discuss this?

Brown: I don't remember. I don't think so.

Heumann: Well, I went to Hebrew school for years. I was born in '47, so it would have been the late sixties, no, late fifties. At thirteen, boys have their bar mitzvahs, but girls didn't have Bar Mitzvahs, or Bat Mitzvahs, at that time. I was in a class of women from the Ocean Parkway Jewish Center who were preparing to do kind of like a confirmation. We all got to get up on stage together and some of us each sang, like, one line of something. I remember that I was nervous about this. Definitely not the do that the boys got. No way. This was very liberal because most places weren't doing anything at that point.

I remember being up on stage—carried up the stairs—and I felt like I made a mistake in one of the notes I was singing, and I started crying. My father had to take me offstage. I remember this. Take me offstage, take me out of the *shul*, take me off someplace. I was mortified. I was crying, I was sobbing. It was, like, "What are you talking about? We didn't hear any mistake." I remember it was with a note, *key*, the word *key* [singing as one does when reading the Torah]: *kee-ee—ee-ee-ee*. I thought I went flat. I died. It was terrible!

They used to call me Sarah Bernhardt when I was younger. You know, sometimes now I start crying when I'm on stage? Now I get a little weepy, but I can keep going forward. I could cry [chuckling]. I could do much more. I don't know where it came from, but it would just, like, be there. I think it was this whole thing of vulnerability and being different. It was more when I was at my family's synagogue, but the breaking up on the *key-ee* was not at that synagogue; it was at the Ocean Parkway Jewish Center.

When it actually came time—I mean, I think there was this coming—anything for me personally was more difficult. But I wasn't arguing for me. I was affected by it, but the way we had designed it, so that it was talking about discrimination and its impact on people, using myself as an example but also being able to give other examples, made me as a rule not feel nervous. I felt I had a conviction, and it was easy for me to fight for that conviction. And I did feel like I was entering into battle, just a change in my physical being. So nervous? Sometimes. But not overwhelmingly so.

Brown: You didn't have to get carried off the set of the "Today Show," sobbing.

Heumann: God, I remember having to be taken down the steps. *Oy*.

Brown: It's a wonderful story.

Heumann: Yes.

Brown: All right. Do you have any other things you'd like to say about the lawsuit or about that time in your life when you were facing that struggle?

Heumann: I think in the office we have the telegram framed when I got the job.

Brown: The telegram from?

Heumann: The Board of Ed.

Brown: They sent you a telegram.

Heumann: Yes, right. And my father framed it.

Brown: You think it's in the office at work?

Heumann: Yes, hanging on the wall.

Brown: Good. So do you want to move on to when you were a teacher?

Heumann: Sure.

Teaching job in public school 219

Brown: A little bit about teaching? As I understand it, the first year that you were teaching, you were teaching disabled kids?

Heumann: Right.

Brown: Just that first year?

Heumann: Right.

Brown: What grades were you teaching?

Heumann: I'm an itinerant teacher.

Brown: Which means?

Heumann: Which means I didn't have my own class. The school that I taught in was not accessible.

Brown: This was [Public School] 219, where you went to school.

Heumann: Right. So the basement was accessible, but the rest of the school wasn't. The only classes in the basement were the classes for disabled children. I taught in every grade, and it felt like I taught any subject that the teacher didn't want to teach. I taught language arts, I taught history, I taught music.

Brown: So did you stay in a room and the kids would come to you?

Heumann: No, I would go from room to room.

Brown: You would go, like, for different parts of the day?

Heumann: For periods. For one period here, one period there. But while I was there, here I was, back in the school that I had gone to school to. Most of the teachers were teachers who had been there when I was a student. I had been quite critical of the educational system [chuckling], so this is the old "what goes around comes around." Of course, it didn't deter me.

I have to say, I started talking to some of the parents about my concerns about what was going on with classes, to try to get them a little organized. I remember there was this one kid—father or mother told me that she was going into a certain teacher's room for the next year—and I said, "Oh, don't. Don't let her go into that room." There weren't a lot of choices here. There were only—what were there?—five or six classes. Yes, that's all there were: five or six classes.

I explained the reason why I thought the kid shouldn't go in there. I didn't think the teacher was a very good teacher. But anyway, the kid went in there. Years later, my mother met them in the neighborhood, and they said that I had been right; they shouldn't have let the kid go there [chuckling], into that classroom. I mean, in the realm of life, it didn't destroy the kid's life, but it did waste a year of it.

Breaks leg

Heumann: I broke my leg in the middle of all this.

Brown: While you were teaching?

Heumann: My first year. I would take a shower by sitting on a beach chair.

Brown: Just a regular beach chair?

Heumann: Yes, a little beach chair. You'd check to make sure the beach chair was not about to fold.

Brown: Stable.

Heumann: Right. So Harry, my friend Arlene's boyfriend, was lifting me. It was very bizarre. I had said, "Harry, check the chair to make sure it's okay." He did. He leaned on it. But he must have leaned on it and, whereas it was probably sturdy in the beginning, however he leaned on it probably made it start folding because he sat me on the chair and the chair folded, and I broke my femur. We had to call the ambulance, and they took me to the city, and I was in the hospital—this is the old days—two weeks. But then I was in a cast for a total of eight.

Brown: Eight weeks?

Heumann: So I was out of work for two months. But as far as my job was concerned, I didn't have my own class anyway, so they just got a substitute. I'm trying to think. When I came back, there was a new principal. His name was Mr. Frank. Mr. Greenwald was the one who had hired me. He retired. Mr. Frank came in. There was one pre-k [pre-kindergarten] class on the floor, and they moved it to a trailer where they had other kids and gave me a class. So the second year I had my own class.

Kept out of evaluation process

Brown: These were disabled kids or nondisabled kids?

Heumann: The second year? Nondisabled kids. The first year other things that happened—because I wasn't a special ed teacher—they wouldn't let me participate in evaluations of kids. What was still going on at that time was that kids were screened. They had to come to school, and they spent a couple of days there, up to a week. They would take the information to this team that had a social worker, an OT [occupational therapist], a PT [physical therapist], speech therapist, a doctor, and they reviewed the kid's record and made a decision as to whether or not the kid could come into school.

I remember being told that I wasn't allowed in because the room wasn't big enough.

Brown: [chuckling]

Heumann: This is what I hate about the system.

Brown: Do you think they actually didn't want you there because they felt that you would advocate to have these kids come to school, whether they thought they should be there or not?

Heumann: I have no idea. They didn't tell me. But they obviously didn't want me there because the room was not too small for my wheelchair. But I remember thinking—I think it was

— 159 —

because of the critical nature that I had spoken about the program. The woman who was supervisor—there was no love lost between the two of us, at all.

Importance of a role model

Heumann: But there was a teacher there, Mrs. Edwards. I really liked her. She was good. It was very interesting to be with these kids who had never—probably, it's fair to say that almost never—had met an adult with a disability in an employed position. So we spent time talking about working.

Brown: These are the disabled kids?

Heumann: Yes. I remember in one of my classes, the older class, I was talking to the kids and talking with them about how it was really important for them to study hard and that even though they weren't being pushed hard in this program, if they expected to be able to do anything, they needed to become a little bit more self-motivated. I don't know what happened to most of the kids. I think one of the kids in my class, Fred Miles, went on to go to college. His father was a doctor; his mother was a teacher.

I met a kid who's no longer a kid. He's now working at an independent living center in upstate New York. He told me that his mother had met me at a meeting of the President's Committee. We had talked about the fact that he lived on Long Island, and they wanted to send him to a program called BOCES, which is a segregated program for disabled kids. I told her not to do that, and she didn't. She was ever thankful that I had really encouraged her not to do that, and he had done very well in school, not having gone to that segregated program.

I felt, as I said, like it was important not just for the children but for the parents, that they had not only someone who was an adult with a disability, but I wasn't the average teacher in the school because of how I had gotten my license, and most of the parents knew about it.

Brown: So do you think that helped the parents with disabled children, sort of watching you through the media go through that?

Heumann: I hope so. I think from people I spoke to, it did. I think it's what parents talk about, ever since I've known parents of disabled kids and I have been an adult, the parents benefit from seeing adults, especially if they're more inclined towards what it is we're supporting. If they don't support integration, then I think they think it's a nice thing but it's not for their kid, so it's good that we're doing it.

Brown: [inaudible]

Heumann: No, it's not that even, but it's just that they see what we're doing as being beneficial to someone other than their children.

Objections of student's parents

Brown: When you had your own class, with the nondisabled kids, you were teaching just all subjects, right?

Heumann: Right. I taught second grade, so I taught the full array of math and science and social studies and reading.

Brown: Did the children react at all to your disability? Did you talk about that, really, with the nondisabled kids? What impact did it have on them?

Heumann: I think I talked about it to the extent that kids asked me questions, which they certainly did. I talked about it to the extent that maybe they would say something, just in the course of conversation, about something related to disability, if it was, like, PC [politically correct]—I wouldn't talk about that. But we didn't really do lessons on disability. Kids always asked questions. They didn't ask them in a scheduled way.

The first year that I was teaching the nondisabled kids, one of the girls came up to me and said, "My mother said to say, 'Merry Christmas' to my sick teacher." I remember saying to her, "Thanks a lot, honey. You can tell your mom that I'm not sick, though."

I had one incident. Well, actually, what I found out was that there were some parents who didn't want me teaching in the school. I'm trying to remember how I was told that. It might have been by another teacher in the school. But I was never officially told it. But there were some kids' parents who had gone to the principal, I was told, who said that they didn't want their kids in my class.

Brown: Parents of nondisabled kids, or disabled kids, or both?

Heumann: No, the parents of disabled kids didn't know the parents of nondisabled kids. They didn't live in the same neighborhoods.

Brown: No. I mean, this happened when you were teaching nondisabled kids?

Heumann: This was not parents of disabled kids. The parents of disabled kids had nothing to do, usually, with the principal of the school. They were in the school, but they were like squatters on a certain level, because whenever they wanted them out of the school, they got them out.

Brown: So the parents probably didn't cause problems or say—

Heumann: Parents of disabled kids. My mother and some of the parents then at that time did because they were unhappy with things that were going on, but as a rule the parents were pretty compliant. The principal usually had very little to do with what was going on. They maybe observed, but there were no consequences for the special ed teachers because they weren't evaluated, really, by the regular principal.

Life in the classroom

Heumann: The second year, I had an aide in my classroom. Most of the other teachers didn't. But I had an aide in my classroom. For the first year I taught nondisabled children, when it was time for me to start teaching, I had gone in and set up my classroom. I think Mrs. Graham was the teacher's aide. She's very good, very nice, and very experienced, and very efficient, and very take-charge. Unfortunately, I think she got sick in the middle of the year, and she was gone. Then I got a Mrs. Washington, who actually was the mother of one of the kids in my class. She had another job. She worked in a bar at night. So she was quite the contrary to my first aide.

When I got my first class, regular class, they lost all my records. Couldn't find them. Told me not to worry, just take whoever came in the room. There was a union contract: you couldn't have more than thirty-two kids. It would all work itself out. So thirty-six kids came into my classroom. I taught in a very big school in Brooklyn. It was a K [kindergarten] through six school, and there were ten classes at each grade level. There were seventy classes. The kindergarten classes maybe had between twenty and twenty-two kids, the first-grade classes had between twenty-five and thirty kids, and the second-grade classes had between twenty-eight and thirty-six kids.

The classes at that time were based on the level of intelligence of the kids, so a two-one was the smartest class. I had a two-six.

Brown: Is that the bottom?

Heumann: To ten. Remember, there were ten classes. So two-ten was the bottom. I didn't have a two-ten; I had two-six. But I had about seven kids in my class who had distinguishable problems. I had a kid named Leroy and a kid named Leonard, a kid named David and a kid named Richard and a girl named Deborah. God, I could see every one of these kids. How many was that? There were a couple of others, but those—Richard, David, Leroy, Leonard, and Deborah—there was Anthony, another one or two. But the five had, like, A-plus issues.

[tape interruption]

Leonard tried to tip my wheelchair over one day. He was a big boy. Leroy was kind of like a baby, and Leonard was like a big bully. He was a child who was seven, but he was a big kid. Leroy was tall also. Leroy was kind of a stringbean, and Leonard was kind of a fighter type, you know [ringing phone].

Heumann: If both of the kids were being bad and you paid attention to one, it made the other kid have more problems. So after Leonard tried to tip me out of the chair, we gave Leonard to another teacher, who had taught more. She had more experience.

I mean, what I wanted to say was that the first day, not only had they lost my records, which I knew before that day, because you came in a couple of days early—like, the week before to put the class together—but as the kids were coming into the room, I remember thinking, I've never in my life been in a regular second-grade classroom, for anybody. So now I was teaching a second-grade classroom, where not only had I never had any

training in how to be a teacher, in a conventional set[ting]—since I had trained myself with other college students—but I had never even been in a classroom with kids who were seven years old, or any years old, because I had never been in a regular classroom in elementary school. I didn't go to a regular class until I was in high school. For a split second, I was, like, Oh, God, this is very interesting. I do remember feeling like this lightning bolt had struck my brain on that.

My experience with those kids, like my experiences with the Upward Bound students and my experiences at the Fort Greene youth center, were that the kids were all inner-city kids. The kids were great, as a rule. To the extent that disability became an issue, it was usually something that they were both understanding of and supportive of and just helped me deal with things. I think that would have been true for most programs, but I think in particular for kids who had experienced—I mean, at that age, they didn't know what they were experiencing, but just the kids who had some difficult times. It wasn't a big deal.

Actually, the young girl whose mother said, "Say 'Merry Christmas' to the sick teacher" was a white kid. I never had any stuff from a black parent. No. Actually, I took kids to my house. I had two kids who came to my house. It was fine. The kids were fine. The parents were fine. I had sent a letter home the first day of my first year of teaching regular classes, with my home phone number on it. I remember some of the teachers being appalled that I was sending a letter to the parents with my phone number on it.

I had an after-school program. I was the only teacher in the school. There was no after-school program. But, you know, I can't remember if one of the reasons I thought about it was because they had difficulty with transportation, but I thought what do these kids do after school? If we could run something after school, that would be a good thing for them. Not being out on the street and getting them to do their homework or do some reading. Now, of course, they put millions and millions of dollars, and they have all kinds of names for these programs. But I did that for a year.

Then I had a problem with the principal because what was going on in the school. New York City was divided by districts, and this was District 18. In the seventies, as more whites were leaving and there were more minority kids in the public schools, there had been some fight in the district between the whites and the blacks. One part of the district was more black, and the other part of the district was more white. There were definitely Puerto Ricans.

Issues of racism and children with disabilities as pawns

[Tape 12, Side A]

Heumann: So, as I had said earlier, the disabled children in the school didn't have a right to be in that school. It wasn't their neighborhood school. They were part of the special ed program through the Board of Education. There was this conflict going on in the district between the white part and the black part. When I went to school there—I left in 1961—the school was a white school. I mean, there were a few black kids, but the special ed classes were racially integrated classes. But in the regular classes, there were a few, but basically all white.

By 1971 the school was basically all non-white. I had one white kid in my class, a kid named Shavonne McGurk. She came in late. I'll never forget this. She came in late. She was, like, a day or two late. She was like a pipe cleaner, kind of like a very thin kid, and little. I mean, seven-year-olds aren't that big, but she was spunky and it was clear she had grown up in this neighborhood, and she knew how to take care of herself. She was a good student, but feisty.

Anyway, so that was the makeup of my class. I had one white kid, and I had a couple of Puerto Rican kids—Diane Rodriguez—God, I remember all these kids. Diane Rodriguez. You would never call her a bad kid, but one day she seemed to be acting out a little bit. I said something to her mom, like, "Could you talk to Diane tonight. She seemed to have a little rough day." The mother comes in the next day and tells me—the mother's first language was Spanish—the mother was very focused on school. She said to me, "Don't worry. There will be no more problems. I had Diane kneel on rice for" I don't know how many hours, "saying Hail Marys."

That's when I realized no one taught me about any of this cultural diversity stuff [chuckling]. I mean, I knew some stuff from where I had worked before, in the African American community. I had friends who were Puerto Ricans. But I had never interacted with families around discipline. So that was—okay—unless a kid was, like, really being bad, skip telling the parent, to sit down and say, "Now, all I wanted was, 'Diane, I hear you didn't have a good day in school,'" not three hours of Hail Marys.

But back to the original story, which is that the race issue was very important. The school was getting larger, and so it was at the point where they couldn't take any more kids in the school. They were busing in New York. The plan was to bus kids from our part of town into the white part of town, and they didn't want that. What they decided to do was to take the disabled kids out of the school and bus them to this other school.

Taking on the Board of Education

Heumann: I, by myself [chuckling], decided that I was going to take on the Board of Education [chuckling] and the principal of the school and District 18 and the teachers union. I can make this short. I'll tell you the story. But I lost. But it wasn't because I didn't really try. I talked to the parents, and I remember I talked to Mrs. Miles. Mrs. Miles was African American. Her husband was a doctor; she was a teacher. She was president of the PTA [Parent Teacher Association] for the disabled classes. They didn't have the same PTA [chuckling].

I said to her, "Look, Mrs. Miles, you really need to understand what's going on. Your kids are being used in a racist situation. You really can't let this happen. It is really setting a terrible precedent to allow these kids to be bused to this other school. You need to say you don't want the kids to be bused out." I talked to some of the teachers. There was one African American teacher in the special ed classes, Mrs. Edwards. I remember—God!—I

spoke to the Board of Ed, I spoke to people from the school district. "You can't do this." I had meetings.

But, of course, I was kind of an island unto myself because I didn't know any of the people. It's not like I could get into my car and go drive around and meet people and stuff, because I couldn't do any of that. All these places were inaccessible anyway. I just thought ultimately right would prevail. The teachers union never met on the floor that I could go to meetings. I didn't even know what was going on because they always met someplace else. Okay. This is the AFT [American Federation of Teachers]. This is a liberal teachers union. So I'm going to ask that they have one meeting on my floor and that we talk about this. So we did.

I explained to them how I thought—because all the teachers were white—how I thought this was completely racist and we had to make sure that this didn't happen, that there were thousands of kids on waiting lists who had disabilities, and if this wasn't being used as a racist thing, then they could put disabled kids in this other school because they weren't expanding the number of classes that kids had to go to school. They voted against me.

So I said, "Okay, I want to talk to the entire teacher body." There were a lot of teachers in that school, right? So we had this reasonably large auditorium, and we had an all-staff meeting one day. I asked to speak. Mr. Frank, the principal, introduced me by saying that Miss Heumann alleged that there were thousands of disabled children on waiting lists. But he had just gotten off the phone with the Board of Education, who said there were no kids on waiting lists. Now she would like to address you.

This one guy got up in the back of the room, who said, "I can't speak to what's going on in New York, but I just came here from Philadelphia, and I know in Philadelphia that is a problem, that there are thousands of kids on waiting lists." That was the only positive thing in all of the months that I was trying to work on this.

Backlash for activism

Heumann: So I got up there, and I explained how I felt this was a racist activity and kids shouldn't be put in the middle of this, and I really would hope they would, in fact, support and say that this was a bad thing to happen. PS: They didn't. But what did happen was Mr. Frank came into my class in May—this was around April, May this was happening—and gave me a very poor evaluation. I was really upset by it because it was very clear that it was totally linked to what had happened, because it was May. It's not like all of a sudden I woke up one day.

I mean, I will never say I was the best teacher in the world, having never student-taught, having had very little support in my classroom. Teachers have burnout in classes today, a lot of teachers leave after the first three years. I was doing a pretty damn good job, and I was doing more than most of those other teachers did. I remember not only the after-school programs that I was running, but you had two open-school times. The first time we had them was one in the afternoon and one in the evening. The second time it was just in the afternoon. I remember I had a big deal with the principal because I said, "We can't just

have it in the afternoon." He says, "Well, nobody is going to come, anyway." I said, "Well, nobody is going to come, for sure, if they're working. They're not going to come. I at least need to be able to give people the opportunity to be able to come."

So they opened the school. They did not want to do that, either, but they did. I was the only teacher in the whole frigging school that had the second time, an open-school. Two parents came. So it was probably two parents that probably wouldn't have come otherwise. I couldn't go to kids' homes and visit their homes and do a lot of the things that would have been good things to do, but neither did the other teachers.

So he wrote me this letter, bad evaluation letter. I went and I talked to Mrs. Edwards, who was the African American teacher. She said to me, "You know why this is happening, and you need to respond to it." So I wrote this scathing letter. I said, "If I'm the bad teacher that you're saying I am, then you certainly shouldn't have been waiting till May to tell me that I was doing such a poor job. You should have been in my classroom much earlier, telling me what I was doing wrong and getting me some support."

But the next year they didn't give me my own class again.

Brown: So your third year of teaching you didn't have your own class?

Heumann: I was itinerant again.

Brown: With disabled kids?

Heumann: No. They moved the disabled kids out.

Brown: Oh, that's right. So you were still on the basement—

Heumann: The whole floor was now second grade, because they moved all the disabled kids out, and they moved all second grade on that floor. Here you had classes that had been set up for eight to twelve kids that had twenty-eight to thirty-two kids in them. I mean, it was completely inappropriate. But they were gone, and they went to this other school. A nicer school, but totally and completely inappropriate.

Experiences prepare Ms. Heumann for future work

Heumann: I didn't get a bad evaluation the next year. I don't know how it went in my record. I have no idea. I mean, they didn't put me on warning or notice or anything like that. It was just a critical letter. That was the kind of thing where, as all this was going on, I didn't intend to leave teaching, really, when I went to graduate school. You had to go to graduate school. You had to have a graduate degree within five years. It could be in anything you wanted.

Brown: This was to maintain your teaching certificate?

Heumann: Right, for everybody in New York, which was good, that you had to have a master's degree. It probably would have been good if they told you to get a master's degree in some subject related to education, but you didn't have to. Horticulture, well, astrology, horticulture would have been potentially relevant. So I was looking at getting my degree in social work, which was kind of funny, given rehab, to be a social worker. But a lot of what I was doing was social work. I wasn't going into social work. I was looking at getting a master's in community organizing from Columbia.

I had actually taken one course at Columbia in community organizing while I was teaching. It was just too much. I had a friend. He drove me up to school, I think it was once a week for a class. I did really well in it. I really loved it. I aced the class. It was great. Which is why I applied to graduate school, and I actually was accepted.

Brown: To that program.

Heumann: To Columbia, which was interesting. I got into Berkeley, got into Columbia. I wasn't afraid in graduate school. It was just something where I finally was taking courses that felt right to me. They were in my areas of expertise, and I felt that I could be competitive, where in a lot of other programs, I didn't feel competitive. I always felt behind because of the lack of appropriate education. I can't compare it to how other people felt, but I never had appropriate instruction until I got into the ninth grade. It was all these years of not having appropriate instruction and then really in the ninth grade, a lot of it was review, but very, very fast review.

If you've had it before, one could argue that it's stupid to teach courses where you're reviewing again because it should be instructed in a different way, but I remember language was hard because I hadn't learned grammar appropriately. English was hard. It's not that I did poorly. I probably graduated with, like, an 88 average from high school. But it was the type of thing where I always felt like if I just had had some appropriate instruction earlier on, high school wouldn't have been something where I was always trying to get through, and praying that it was over, and worrying about tests all the time.

Any time there were lectures or discussion, I always did well. I remember my parents coming back from open-school night one year, being told that I did really well in class, my homework was good, but when I took a test it was, like, all these teachers individually said, "She looks like another person when she comes in to take tests." So when I was teaching the disabled kids, it was really partly based on those experiences, that I was trying to get the kids to focus on school.

You couldn't fault part of what was going on there. The small classes. You couldn't say small classes were bad. They weren't all on one grade, either. But the instruction. I mean, the teachers just weren't prepared. They, in part, weren't prepared because they weren't taught. They didn't have the same books, for example. The year that I taught second grade, had my own class, I remember that I offered to share my books with them. I offered to have kids come into my class. Nothing ever happened like that. They never got any integration.

The classes, the special ed classes. They had some kids who had mild mental retardation, but mainly they were physically disabled kids who at most had mild mental retardation. The truth is, a lot of the kids in my class were socially disadvantaged, and so there was no discrepancy between these kids, and to the extent that there was, it didn't matter anyway, because the kids could all benefit each other.

I think all of that was very helpful for me in a lot of the work that I was doing—the DIA work that I did and the work that I did at CIL [Center for Independent Living] and the work I did at WID [World Institute on Disability] and now, certainly, in this job. While things change, unfortunately they haven't changed that much.

Expectations for students

Brown: Part of the problem was low expectations? Is that something that you tried to—

Heumann: I didn't have low expectations. I didn't have low expectations for any of my kids. I mean, I always felt that all these kids could achieve if they could get what they needed. In part, that's why I ran the after-school program. I thought, okay, if I can give them another hour and a half to two hours in school and we can be reading and we can—as I said, all the things—everybody is, like, "Oh, we need to do after-school programs" and blah-blah-blah.

It would have been great had the school really had an after-school program where we would have brought tutors in. The reading levels of a lot of the kids were below second grade. I did have some kids that were on grade level, but certainly not many who were above grade level, if any.

There was abusiveness that went on between the regular teachers and the nondisabled kids. The kids were having problems who didn't conform. The classes were too big, and we were lucky at that point. We did have a school psychologist.

Brown: You did?

Heumann: We did. A lot of schools don't have them anymore. She was helpful. But there was just a lot of problems. I felt very early on that these aren't the fault of the kids, and there are ways of getting to these kids to make them feel valued. A lot of the parents were very nice. They wanted to do right by their kids. It was a very good experience.

The next year, when I had an itinerant program, it was okay. It allowed me to do more of my DIA work. Having your own class was harder work, on a certain level. Again, you taught a bunch of subjects. I wasn't, like, the math teacher or the reading teacher. I taught a bunch of different classes.

Brown: Did you always teach the same group of kids the same things? Do you know what I mean?

Heumann: Yes. I had, like, black history or I had social studies—whatever it was.

Brown: You changed every day what you were going to be—

Heumann: You know, I can't—

Brown: —teaching to which class.

Heumann: No, I don't think so, no, no. I had five or six classes, so you just went from class to class. I had no attendant.

Brown: What did you do?

Heumann: Going to the bathroom?

Brown: Yes.

Heumann: I don't think I went, as a rule. I'm trying to remember. They did have the accessible bathrooms, actually, in the rooms. I was able to go myself. I mean, I can't now, but I could then. But I think there were definitely days when I didn't go at all, and there wasn't anybody that could really help me. The woman who was the aide that one year, she never helped me. I wouldn't even ask. I was afraid to ask. Certainly, with everything going on at that point, the last thing I thought about was asking for help in the classroom, to personally help me. I didn't know anybody who did it, number one. But I just thought this was beyond—they'd go crazy.

Impact on children in classroom

Brown: I wanted to go back to something that I asked about before, which was the impact that you think you had on the disabled kids that you taught. If you have maybe concrete examples of what kind of an impact or effect you think you had.

Heumann: Yes. It was what I was saying earlier. You know, it's something that I don't know for sure because I didn't see most of them again. I did hear that some kid—there was some article in the paper about me—and the kid did have it hanging up. The story of the parent who had met my mother on the street, who had said that I had been right, that she's sorry she hadn't listened to me and put her kid in another classroom because it was a wasted year for her kid. This other young man, who I met when I was on this job, who told me that his mother talked about me and how she was glad that she had listened to what I had to say. Stories like that. But, as a rule, I can just surmise that I'm sure it was certainly not a bad experience for the kids.

To the extent that anybody ever asked them about it, I'm sure they thought it was kind of neat to have a disabled teacher. But I guess there was this one class, older class, where I had asked them, towards the end of the year, what they wanted to do when they grew up, and most of them said that they wanted to be teachers. I remember I was upset. I said, "There are many more opportunities out there than to be teachers." Then I thought it's probably the first time most of them wanted to be in a professional position, so, hey.

Brown: Let it go.

Heumann: Try to get this job. See what happens, you know.

— 169 —

Brown: Right, right. I'm realizing, as well, when I ask the question I think I'm looking for something different, but I realize that there's no way that you would be able to see it because you don't see what happens with disabled kids when they're with you because you don't see them when you're not there.

Heumann: Exactly.

Brown: Whereas I do see the difference. As soon as they see you, when we've done site visits together, just the way that they look at you and they know who you are, or they have some inkling that you work for the President, and just the amazing difference in how they look to me. I can imagine it probably had a much larger impact than you can obviously even imagine.

Heumann: I'd love to know what happened to some of those kids. Some of them, I'm sure, are dead because they had muscular dystrophy. I had one kid in my class whose brother I had gone to school with. The brother was dead of muscular dystrophy. I can't remember if I had one or two of them, but there were seven brothers who had muscular dystrophy.

Brown: In one family, you're saying?

Heumann: Yes. The mother—there were nine kids that the mother had had, but her family, her brothers and sisters—there were eleven kids. I don't know. Eight, nine of the kids—all of the boys, with the exception of one, who became a priest—

Brown: Does that seems somehow connected?

Heumann: Well, I thought it was kind of interesting, actually. But none of the girls had it. But all the boys except this one guy that became a priest. The Rinaldis. I remember the Rinaldis. It's amazing how I remember these names.

Brown: It is amazing that you do. It doesn't seem that you could have remembered the names of the kids when you were an itinerant teacher as well as the ones when you were with them all the time.

Heumann: No, I don't.

Brown: I have two more questions.

Heumann: Okay.

Comments on teaching

Brown: I think that I know the answer, but I'd like you to talk about it a little. Did you like teaching?

Heumann: I did like teaching. It was a little frustrating for me. There were a couple of things going on. One, I was the president of DIA at the same time, so that was a lot of work. One of the criticisms that still goes on in the school about education is how teachers don't work together, don't collaborate together. For me, as a new teacher, I really had no support. The only thing I thought about when another principal, a vice principal, came in the classroom, was not that anybody was coming in to sit down and observe me and then have a meeting with me to talk about "try this, try that." But they were going to write me up. I didn't think, except when this one incident happened, I mean, I had been evaluated before, but it wasn't constructive.

I think the kids did well by me. I think I taught in a grade level that I really enjoyed teaching. I liked the second grade because the kids were old enough and not too old. I really felt that I learned a lot from my father. I mean, I felt in that classroom that there was more of what my father had taught me being taught than anything else. I would go back and think about what my father required of us, and it was always a lot.

So the kids ragged on me for the amount of homework they got. We were required to give homework every night, and I did give homework every night. It wasn't anything uniform. We all didn't give the same kind of homework. It was, okay, so what am I going to do for homework? I tried to do some innovative things, outside of giving the kids math problems. I remember I had the kids watch—what was it called?—not "Sesame Street" but the program that came on after that.

Brown: "The Electric Company"?

Heumann: "The Electric Company," so they had to watch "The Electric Company," and they'd have to pick out five words from "The Electric Company" and either write five sentences or a story or different things like that. At least then, I figured, okay, they're watching TV, which is what they're going to do anyway. But at least get them to watch something which they'll learn something from. I really enjoyed working with the kids.

I always liked the kids who had the most problems. Those were the kids that I was always most challenged by because I felt if I could help those kids, then I was really going to make a difference. The kid who had the most difficulty in my class—I don't know what happened to him, but I know that—I actually got a friend of mine, Jack Geckelman, who was a teacher, to take David home on a couple of weekends. Did I tell you this?

Brown: [no audible response]

Heumann: David had stolen money in school once. He had seen the school psychologist, and after his visit with the school psychologist, there was an announcement on the intercom system that her wallet was missing and that anybody who found her wallet she would take out for ice cream. She came to me and told me she thought it was David because she said, "Because I've looked"—and then the wallet appeared. She came back to me and said, "I thought it was David because it was after he left that the wallet was gone, and I tore the place apart, and I looked in the closet" and blah—blah-blah. Then she found it in the closet. But she took him out for ice cream.

Jack took him home a couple of weekends. One weekend he stole fifty or a hundred dollars, and Jack never brought him back again. I said, "Jack, you know, talk to him. Confront him directly on it because he needs to know that you think he did it and that you can't trust him." But he never did. Never talked to him again. I mean, I talked to him, but

I also felt like what had happened between Jack and David was between Jack and David, and that Jack needed to say something to him. But, you know, of course, he did something bad, and he wasn't confronted on it. It was fifty, a hundred, but it was a lot of money for a seven-year-old kid to take.

Then I heard that he was arrested in the fourth grade for stealing a car. He wasn't any taller than me, sitting in my wheelchair. I remember people saying they don't know how he stole the car because he had to be, like, *way* down. But God knows, he was a smart kid. It's really a shame. Mrs. Graham and I liked David the most because he really was a smart kid. There was no father in the family. His mother was a prostitute. His grandmother was an alcoholic. His aunt was a drug addict. His brother was mentally retarded. The older sister was frequently truant, taking care of the kid.

I remember thinking, God, this is like out of a social-work book. He was known, obviously, throughout the school for his problems. He always stayed in the after-school program. One day he hid in a closet, and he said he wanted to sleep there overnight. I remember thinking, I can't believe I'm having to send this kid home. Let him sleep in the frigging closet. We had a bathroom there, you know. He could sleep there, as far as I was concerned. It had been a preschool class, so they had a bathroom there. I'll give him food, stick a TV in there.

[Tape 12, Side B]

Heumann: He had measles or chicken pox. He had spots all over his face. I remember I had to tell the nurse about it, and so they sent him home. One of his relatives came to pick him up. I remember him running around the hall, like he was climbing the walls. He didn't want to go home. I wasn't allowed to keep him in school because he was contagious, but apparently he wasn't contagious anymore because once it comes out, he's not contagious, but it's dangerous for the kids to be out; they need to be home. Kids would come in and tell me they'd seen David outside. He didn't come to school, but he was outside. I don't know what happened to him. I would have liked to find out about him, though, if he's still alive. How old would he be now? It was '72 that I had him in my class, and he was seven, so he'd be pretty old, actually.

Brown: My age.

Heumann: Yes. I don't know how to find him. All right.

Heading to graduate school

Brown: So the reason that you stopped teaching was to go to graduate school?

Heumann: Right.

Brown: Did you intend to go back to teaching at that point, or were you already thinking in terms of working—

Heumann: I didn't intend not to go back. I don't think I could answer affirmatively that I intended to go back, but I clearly hadn't thought of not going back. I think, had I stayed in New York and gotten my degree at Columbia, especially in what I got it in—was accepted in community organizing. I may well have gone back. I think it would have given me some additional skills. Who knows? This is all speculation. I could have gone back in that kind of position, you know.

But in California, once I was there, I didn't look to go back to New York. I didn't have a credential in California, and I would have had to get another credential.

Brown: With more stringent requirements?

Heumann: No, I doubt it. New York City probably had the most stringent requirements in the country.

Brown: But your New York credential wouldn't transfer to California?

Heumann: No. Most states didn't transfer.

Brown: So you would have had to take tests again?

Heumann: Yes, I'm sure. I don't know what they were, but at that point I didn't think about it any more, because I came out to D.C. I did my work there, and then I came to D.C. At that point, it was, like, gone. No one calls you. No one from the Board of Ed called to say, "What's up? What's going on? Two years are up. Almost finished? Ready to come back?" Right. You were another number! They didn't care. I'm sure it just happened to anybody. You took a leave—because I was on leave.

Brown: You said there's a lot of burnout in the first few years, so probably people would say they were leaving to go to graduate school, and maybe they did. Probably a lot of people didn't come back after that.

Heumann: Right. That's still true today. You should be a teacher. They're having so much difficulty recruiting teachers.

Brown: Well, I'll have a lot more experience when I come back from the Peace Corps.

Heumann: Yes, yes.

Brown: Anything else you want to say about your teaching job? Then we can call it an interview.

Heumann: No, we only talked about adult ed. We didn't talk about any of my college instruction. We didn't talk about the course I taught at Berkeley.

Brown: Oh, no, no, no. I'm sorry. I misunderstood. I thought you meant teaching that you did while you were in college.

Heumann: No.

Brown: So that's that. See you next time.

IX. Disabled in Action, New York City, 1970-1973

Disabled in Action forms in New York City

[Interview 9: February 15, 1999] [Tape 13, Side A]

Brown: So tell me how Disabled in Action in New York got started.

Heumann: During my lawsuit for the teaching position in New York, as we had talked about, there were lots of people who were interested in what was happening. I was getting a lot of phone calls and a lot of letters, just people expressing interest. A number of my friends and I had—I think for the years previous, for three or four years—had been going to different meetings for different organizations, trying to find a place that we felt represented what our interests were in a political organization.

We had been involved in a couple of different groups, but they, from my recollection, tended to focus on issues—an issue, an architectural barriers issue—they weren't organizations that really spanned cross-disability and cross-issues. We were really interested in an organization that did that: crossed over disability lines and crossed over issue lines.

So as we were moving forward with this lawsuit, I think Denise McQuade and I and a couple of other people decided that maybe what we ought to do was to try to start an organization. The way we would do it would be to gather up all the names of the people that had been writing to us, plus friends and other people that we knew, and invite them to a meeting, which happened at Long Island University, and see, basically, if there <u>was</u> an interest in starting an organization.

So we did that. We had about eighty-some people who came to the meeting.

Brown: That was the one in May?

Heumann: No, I think it was in February or March.

Brown: Because there was a meeting in May in 1970.

Heumann: It was earlier, I believe. It was when we formed the organization, which for one week was called Handicapped in Action.

Brown: For one week?

Heumann: Oh, I hated the name, so I lobbied everybody on the phone to change it.

Brown: And it worked?

Heumann: We had a democratic election, which we democratically changed [chuckling]. Yes, I thought Handicapped in Action was much to retro. At that point, in the seventies, "disabled" was not a word that was being used a lot here in the States, but it was a word that was being used in Scandinavia. They had already done their analysis of what was wrong with "handicapped," so it seemed that if we were supposed to be starting a progressive organization, starting it with the word "handicapped" was not exactly on the right track. So we changed the name. I really do think it was a week that the name existed as Handicapped in Action.

Brown: How did you know what the Scandinavians were doing? Were you already in touch with people internationally at that point?

Heumann: No, just from reading I got a lot of newsletters. *Accent on Living* might have had a piece in it. I hadn't been to Europe yet, and I hadn't really, to the best of my recollection, met any people. It must have been from readings because I do definitely remember that I knew what the issue was around "handicapped" versus "disabled."

Brown: And you were already using "disabled" to define yourself?

Heumann: Yes, I believe I was. It was maybe in transition, but I can't remember whether I was. I have to go back and look at the articles to see how I defined myself, but I probably was. At any rate, so that's how Disabled in Action started. We had a meeting, which was cross-disability and was intended to deal with cross-disability issues.

Have you talked to Frieda Zames? You should talk to Frieda because she'd have all the original documents. We worked on our bylaws and our board of directors in the very beginning, obviously, and I assume if anybody has got the documents, it would be she.

Female-dominant Board of Directors

Heumann: At any rate, the board primarily was made up of women. I believe we had two men on the board, Jimmy Lynch and Larry Weissberger. Larry was a social worker, and Jimmy had muscular dystrophy. He passed away. I believe it was Frieda Tankus and Bobbi Linn—but I'm not sure whether Bobbi was on the original board—Roni Stier, Denise McQuade, Susan Marcus. I don't remember everyone. It wasn't that big a board. Same names?

Brown: Pretty much. Frieda had a brother named Martin.

Heumann: No, Morton. Morton Tankus.

Brown: What about Pat?

Heumann: Figueroa.

Brown: Denise Figueroa?

Heumann: Denise wouldn't have been involved. Pat wasn't on the original board. I don't think there were more than two men, really. It was kind of a joke that we put these guys on, so that it would be integrated. Kind of like WID used to be called the Women's Institute on Disability.

At any rate, we over time structured ourselves in a way that we had committees, and the committees focused on a wide variety of issues. God, I wish somebody had all of that. I think we had a transportation committee, we were dealing with physical access issues, we had a committee on sheltered workshops, we were dealing with the Jerry Lewis telethon.

Committee structure

Brown: Did you have one on education?

Heumann: I don't believe we had one on education per se. We were dealing with issues that were most pressing in relationship to what was actually going on in the community, so workshops were definitely a big deal, physical access was a big deal.

Brown: Transportation.

Heumann: Transportation was a big deal. Housing, maybe. We had one on [housing], too. But we were very active. The board met pretty regularly. We had meetings, I believe, a couple of times a year for the bigger part of the organization, and I think we were reasonably democratic. We tried to move our meetings around to different people's houses, for some of those people, like Roni and myself and Jimmy, who couldn't drive. Then there were people like Denise and Susan, who could.

We might have been dealing with some benefit issues. God, it would be helpful if Frieda had any of that stuff, because if I saw it, I could really remember it better. But basically I think our method overall was we identified an issue that we were concerned about, and we would figure out a plan of what we wanted to do in order to be able to deal with it. It usually would be anything from letter-writing campaigns to meetings with officials, to testifying.

— 176 —

Organized demonstrations

Heumann: We had numbers of demonstrations. As a rule, we didn't start with demonstrations. As a rule, we wanted always for people to not be able to say that we were hot-headed. We wanted to be able to lay out and say, This is what we saw about the problem; this is what we tried to do with the problem; and the reason why we were doing this was because people wouldn't meet with us or wouldn't talk to us or didn't listen to us or wouldn't make changes.

We were the first group, I think, that organized demonstrations against the Jerry Lewis telethon. That was way before anybody was doing that. We actually had some of the members who went to the telethon and sat outside the telethon and fasted, so there were hunger strikes that were going on for a day, with people with muscular dystrophy. We tried to get people who were affected by issues to be the ones to take a primary position because it seemed like if people with muscular dystrophy didn't oppose the Jerry Lewis telethon, was it right for those of us who didn't have muscular dystrophy to oppose the Jerry Lewis telethon? People like Jimmy Lynch hated the Jerry Lewis telethon.

The things that I remember, we were always working. We were doing newsletters, we were doing mailings, we got my mother involved, I think Denise's mother involved. We were always answering letters because we were getting lots of letters, and I did dictations over the phone to Denise McQuade, who would take these letters down and answer these letters. But there was a lot of stuff going on because we definitely were the more radical organization in the city at that time and, from what I could tell, really, around the United States.

CIL was an absolute nonentity on the national level. The Disabled Students' Program [Physically Disabled Students' Program at UC Berkeley]—nobody ever heard of them.

Brown: Had you heard of them at this point?

Heumann: Never, never. We knew it was going on in parts of the country. There was stuff going on in Boston, there was stuff going on in Illinois.

Brown: "Stuff" meaning protests and demonstrations?

Heumann: There were organizations that were developing. We'd get calls from people, like Nancy Kennedy. I remember Nancy Kennedy calling me. I believe I was still in New York, and I think she was at SIU [Southern Illinois University]. People like Nancy calling and just "read about you, heard about this, we're working on this." But didn't really hear much about the West, nothing.

Brown: So the letters you got were not just from people in New York.

Heumann: They were letters from different people. New York or other places. They were typically more personal letters. The people were having a problem with this, that, or the other thing, and they wanted help: what to do, where to go. I don't know if we have any of those. Does Denise have any of that stuff?

— 177 —

Brown: I don't think she said she did, but—

Heumann: Well—

Brown: Now, what would you do with it? I'm assuming it's the same kind of letters we used to get at WID all the time, the same sorts of calls to the information and referral department. "My kid has a disability, and they're not let[ting] them into school" or "I have spinal cord injury and I can't get out of the nursing home" or whatever. How did you refer these people? What did you do with a letter like that?

Heumann: We just answered it to the best of our ability, referring them to people that we thought maybe could help them, or just giving them information about what we thought they might want to do. We had no staff. We all were working full time. But I don't know where the stuff is. I had a whole file cabinet with all the stuff, all the letters. Everything was filed and organized at my Willoughby Street address. I have no idea what happened to that stuff. Too bad. It would be very interesting, too. The newsletters would be interesting to look at. Frieda might have some of those. Denise didn't have any?

Brown: I didn't ask her if she did. I don't know.

Heumann: Those would be interesting because there would be a column from the president, things like that.

Governor Rockefeller's office sit-in

Heumann: I remember we had a demonstration outside of [then Governor Nelson] Rockefeller's office. It had to do with some work that was being done on some architectural barriers law. I can't remember if it was a matter of enforcement or a piece of legislation. But I remember we wanted to have a meeting with him, and they wouldn't let us in. We had this big demonstration—big in my mind, not big in relationship to any other regular demonstration—but big for us.

I remember it was the first time that we ever tried to break our way into a place. I remember somebody pushing our wheelchairs in, trying to push in the door and trying to force our way in because they wouldn't let us in for a meeting.

Brown: This was whose office?

Heumann: The governor's office. But it was in New York City.

Brown: So did you get in?

Heumann: No, we never got in. They never let us in. But we had a great demonstration.

— 178 —

Involvement with Willowbrook State School for the Mentally Retarded

Heumann: I remember we got involved with the group from Willowbrook State School for the Mentally Retarded. We knew about it, but we didn't know how to get involved with them. Then one day there was a little article in *The New York Times* about a meeting that was going to be held around the Willowbrook situation, so we sent some people to that meeting. I went, and some other people went. We started getting involved with them.

That was a whole different group of people. They were politically really on the left. I mean, they were kind of not like us, who were just stumbling through and moving along and doing. We didn't have political ideology. We weren't based in any political organization. We were just setting up DIA, and we had progressive views. But we met there. Bill Bronston was there. He was one of the doctors. He's in Sacramento now. He was one of the doctors who had actually gotten Geraldo Rivera to come in and do the exposé.

There was a guy there named Richard Levy, who was their attorney. I believe Diane McCourt was there, Malachy McCourt's wife—you know, the guy whose brother wrote the book—ashes—current.

Brown: *Angela's Ashes* ?

Heumann: *Angela's Ashes*. Malachy's wife, Diane. They had a developmentally disabled daughter. I actually knew Malachy from this group. We got involved with them. I was involved with them for a couple of years. Actually went out with Richard Levy for a while.

Brown: Ooh, ooh. Do tell. Tell the interesting part, if you want to. [laughing]

Heumann: I'll get back to that. But that was very good for us because it A) got us into another issue, institutionalization issue, which got us involved with things like [Wolf] Wolfensberger's normalization activities and some of the stuff going on at Syracuse. I think that's when I met Doug Biklen. I also visited Willowbrook with a reporter and a nun. I remember going out there and visiting it. They weren't going to let me in because I was in a wheelchair.

Brown: What was their reasoning?

Heumann: I could get hurt. Something could happen to me. Me, I was afraid they weren't going to let me out. That was my fear once I got there. They wanted me to sign a piece of paper to say that if anything happened to me, they weren't responsible. I don't believe I signed it. I believe I said to them, "You're not asking these people to sign a paper like that. I'm not going to sign any paper like that." So I don't believe I did.

Warehousing of people with disabilities

Heumann: But we did go in and visit. Of course, at that point it was better than it had been because this whole exposé had occurred. It was a pretty bizarre place. I remember they had a room

for babies, like below three. There was this big room, and they had these mats laid out all on the floor, and they had these kids laying on the mats, laying off the mats. They had televisions that were mounted on the wall, and the staff was sitting around, doing nothing with the kids, really.

Then there was a wall. I asked what was behind the wall. It had a door, you know? So they took us in there, and there were all these babies in these cribs, tied in the cribs. Kids with hydrocephalic conditions and just all kinds of kids either tied in the bed or just in the bed. But there was nothing going on. I remember when we left that unit, they said it was very important to wash your hands because disease was caught here, and you had to wash your hands really well so you didn't have to worry about contracting any diseases. But I remember this starkness of nothingness going on there.

Then we went and visited another room, where people were older. There was basically nothing going on anywhere. We visited this other big unit, where there were more adults. They were dressed. There were no people sitting around undressed like you'd seen in the exposé, but there were lots of people, nothing really happening, people kind of sitting in corners, rocking, standing, sitting on the floor.

Then we went to this other room—big, room—where there were primarily people laying in what I called Eliza Doolittle flower carts. They were like wagons made out of, I think, wood. They literally were like a wagon. They had wheels on them. There were people just laying in these, all contracted. I went over and tried to talk to some of the people there, and it was like they were dead. They were not dead, but they were dead. They hadn't had any interaction for so long that they didn't track fingers, they didn't respond to snaps, they didn't respond to anything. They were just lining this room, like in rows. But there were a couple of people there in that room who could walk. I remember this one woman—or woman maybe not so young—was sitting in a rocking chair. But, again, it was this lifelessness everywhere, this kind of insanity.

"Beautiful building" and functional people with disabilities

Heumann: Then they took us to this other place. It was so bizarre. It was another building, not very large and not many people in it. Very active. They had a garden. Disabled people. Had a garden. They had a fish tank. They were this group of living, disabled people who were given a lot of support and nurturing and were dressed well. The room was decorated well. It was like so totally bizarre. In the middle of this hellhole was this beautiful—I mean, "beautiful" is definitely an exaggeration of what "beautiful" is—but relative to that place, it was the beautiful part of the place.

I remember just thinking how totally crazy this was. That was very important for me because I had worked with some people with cognitive disabilities. When I had gone to elementary school, there were some kids who had cognitive disabilities, and then, when I was teaching the first year I taught, and when I went to camp—so it's not that I didn't know any people with cognitive disabilities—but the people I knew were primarily still living with their families. Although the system didn't have high expectations for them, they were with their families. They were more than less doing well with their families, sisters, brothers, things like that.

This was just people who maybe had been abandoned. You didn't know the story behind why everybody was there, but it was very compelling. When I think about things that I remember, that visit is like it happened yesterday. So we did a lot of work with them, with that group. I can't remember its name. I don't remember. [Policy in Action Coalition (PAC)]. But Adrienne Asch was involved with them, too. I think we must have gotten her involved somehow.

Brown: You already knew Adrienne?

Heumann: Yes. I think I did. I don't remember.

Brown: Was Joe Shapiro involved with Willowbrook at that time?

Heumann: Joe Shapiro, no. Nobody knew anything about Joe Shapiro. Joe Shapiro didn't get involved until the eighties.

But the thing in New York was that everything was big, so it was huge. There were thousands of people there, and I hadn't seen the whole place, for sure. I definitely think it was two to three thousand people there. Maybe I'm wrong, but I don't think so.

Brown: What was their explanation for why the people that had the, quote, "better treatment" were in such a different situation?

Heumann: I don't know that they had an explanation. It was just these were people who were clearly more articulate. These were not people who had significant cognitive disabilities. These were people that you could see the staff and others could relate to easily, without a lot of services. My recollection was some of them might have been mildly retarded, but not all of them. They were just regular kind of people who might have been put there for who knows what reason. Because lots of people were put there.

Brown: Were a lot of those people people who just had physical disabilities and their families didn't want to deal with them?

Heumann: I wasn't there long enough to find out why they were there. But it was typical in those days, where people would just suggest to families that they put the kids in an institution, or the families couldn't take care of the person, for whatever the reason was, and they wound up in these different [institutions]—I mean, Willowbrook was just one.

Brown: So it wasn't just for people with mental retardation?

Heumann: It was significantly for people who had cognitive disabilities, really. Most of the people that I saw there. Of course, you know, when you see people who have been in a place like this for so long, they might have been slow, just because of economic situations—not having the appropriate stimulus or support at home—but clearly not everyone in that place had significant cognitive disabilities. They were much more engaging, much more alert. You could interact with them. But you could also tell that many of these people, with a little bit of support, were right there to be able to interact.

I met Bernard, this guy there named Bernard—whom Bill would know—I can't remember his last name now. [Carabello] But he's still active, I want to say with UCP [United Cerebral Palsy]. He became friends with Geraldo Rivera.

Brown: He was an inmate?

Heumann: Yes. Right. He actually, I believe, was on Geraldo's show a number of times. He was an example of a young person who had been there a long time and—you know, might at that point have some mild cognitive disability—had cerebral palsy. But I think for many of us in DIA, the Willowbrook situation really epitomized what could be happening to people. It also, for us, was the fact that we really did want to be a cross-disability organization, and so it really did enable us to do work with that group.

DIA sheltered workshop committee

Heumann: Neil Jacobson was on the sheltered workshop committee. I mean, here you had this group of young people. We were in our twenties. But we hated sheltered workshops because they had tried to get so many of us into a sheltered workshop. Stevie Hofmann was somebody who was also very actively involved. He's in California now. But Steve, I believe—and Carol Camarata. I think Carol actually was sent for an evaluation at a sheltered workshop. I think she was a quad polio. They wanted her to do something like stuff envelopes, and she couldn't use her hands. I mean, these bizarre stories. I think it was Neil and myself and Steve.

Neil Jacobson and Stevie Hofmann. Steve Hofmann had cerebral palsy. He was significantly involved, motorically, speech-wise, with his legs. I think he also was sent to a sheltered workshop for an assessment. Well, first of all, nobody should have been there, period. But the lunacy of it was that they were asking people to do things that there would be no way they could do, and so then you would be evaluated and paid below minimum wage because you couldn't produce the number of pieces that you needed to produce to be competitive. Well, of course not. If they couldn't use their hands, how could they be stuffing envelopes and doing ridiculous things like that?

So that was one of the reasons why we were involved in that issue, because some of the people in the organization just felt strongly about it. I remember one day we went to visit a sheltered workshop. We had a meeting with one of the executives at the sheltered workshop. I don't remember which one. In Manhattan, though. I remember this guy telling me that people had a choice. No one forced people to come to a sheltered workshop. If they really didn't like it there, they didn't have to come. I remember saying to him I didn't think people were really being given a choice if their choice was staying at home or coming out, at least being here. It didn't seem to me that was a choice.

We were dealing with issues around minimum wage.

DIA on the national scene

[Tape 13, Side B]

Heumann: We were involved in many different activities. I was there three years. I remember broad things. One of our first activities was going down to the President's Committee [President's Committee on Employment of the Handicapped]. Did we talk about this?

Brown: This was the first time that you went?

Heumann: Yes.

Brown: Was it a big struggle with the letters?

Heumann: Right. Yes, you did hear something about it.

Brown: No, I studied. I just did my research on it and read some articles on it.

Heumann: Okay. We were kind of candy-store approach and worldly approach or kamikaze approach. It was just, like, okay, there are a hundred issues. Some people would say, "Focus on two," but myself and others were kind of more into focus on many. I think in part it was because we wanted to get exposure. We kept searching, and it was really searching for where is the power? Who are the power brokers, and how can we influence them? I think you kind of naturally—I don't know about for anybody else, but for me and some of us that were working on this—it was a natural evolution to move out of just dealing with city issues. When you looked at things they were impacted on by the state and the federal level.

DIA meeting at the President's Committee on Employment of the Handicapped

Heumann: We had heard about this President's Committee, probably was from *Accent on Living*. At that time, *Accent on Living*, which is still around, was the main publication. A lot of us got it. Ray Cheever is a nice guy. He never was like what you would call a progressive. Ray is still alive; he'd be an interesting one to talk to because he definitely knew me.

But at any rate, we contacted the President's Committee and asked for a room to hold a meeting. They told us that we were too late and we couldn't have a room. I remember we were outraged. This is a government-run event. How can they not give us a room? They don't want to give us a room because they were afraid of what we were going to do. We hadn't even thought of doing anything, but just the fact that they didn't want us there made us feel like, Oh, well, we've got to think about doing something.

So we contacted Congressman Badillo, Herman Badillo. I don't remember whether we called him or wrote a letter, but next thing we knew, we had a room because Badillo's office had contacted the President's Committee and told them to give us a room. So we got down there. We held a meeting (we always were holding meetings). We had fliers. We invited people to come and talk with us and meet with us. This would have been, I think, in '71.

Brown: So you didn't know anybody on the President's Committee and you hadn't been to any of their meetings before?

Heumann: No.

Brown: Did you have an agenda? Did you want to be on their agenda? Were you on their program?

Heumann: I don't remember if we had a workshop.

Brown: It was a Disabled in Action meeting, and you were inviting people to come find out about what you were doing? What was the function of—

Heumann: That's what I'm saying. Looking at some of the newsletters would be helpful. We were down there, I think, because [President Richard M.] Nixon—it was the President's committee. You know, you thought the President would come. I'm trying to remember if it was the first year or the second year that we organized a walk-out.

Brown: It was the next year.

Heumann: Second year, right? Seventy-two?

Brown: Seventy-three.

Heumann: No, we had two actions, '72 and '73. There were two walk-outs. The one that was in '73, with Julie Eisenhower?

Brown: That was '73.

Heumann: I believe we did something in '72 also.

Brown: You know, that's interesting because Denise said that in '72 you organized the disruption of Julie Eisenhower's speech.

Heumann: That's right.

Brown: But the press—I mean, what I found, the actual article—it said it was in '73. Did she speak twice?

Heumann: It's possible, but I definitely remember doing two things. '73 was the time when there was also a Lincoln Memorial march, right? We did something the year before, in '72. That's when we had a march to the Capitol.

Brown: There was a march to Capitol Hill in '73 as well.

Heumann: Right.

Brown: A candlelight vigil. That all happened in '73.

Heumann: Right. But there was also something that happened in '72. And Denise remembers that, too, right?

Brown: She remembered '72. She thought it was a rally, maybe, or a march? She couldn't really remember. In '73, she said, there was a march and candlelight vigil.

Heumann: Right, right. We stayed all night at the—yes, we did something in '72 and '73.

Brown: She said something about a parallel conference of sorts that was more activism-oriented, which she thought was in '71 but, again, she wasn't sure. It might have been in '72.

Heumann: Yes, that's why we've got to get the newsletters because we would have stuff in the newsletters, I think. She doesn't have any of the minutes?

Brown: Didn't ask.

Heumann: Okay. She's probably the best one to ask. At any rate, we began to get to talk to people. You had disabled people there who were, as a rule, the more conventional types.

Brown: This was at the President's Committee?

Heumann: At the President's Committee meeting.

Brown: Are we talking about the first one?

Heumann: In general, but in '72 and '73 we used it more as a place to get people to come. Like the demonstrations in '77, anything where there was a place made it much easier for us because we didn't have to deal with transportation. So we rented rooms in the hotel, we put twenty-nine thousand people in the rooms [and] that was that. We had our headquarters there. Ralf Hotchkiss was there. When did Ralf come? I started teaching in September of '70, right? I think

I met Ralf in spring of '71. So he might have even been there with us for the first President's Committee meeting, because he lived in D.C.

Brown: Had you been to D.C. before you came down for the President's Committee?

Heumann: I don't think so. I dated Ralf for a while.

Brown: Ooh, ooh. Dish.

Heumann: I'm trying to remember if I had been down there before the meeting or then went back to see Ralf a couple of times. At any rate, we were learning the lay of the land. There were a lot of meetings. We went to those meetings and some of their workshops. Things cost money so we as a rule didn't go to the dinner. It was a time to organize, learn, try to have some influence, but just, basically, get on the national scene. I don't remember if we went over to the Hill the first year.

But the second year would have been '72, in May. The election was in November of '72, right? Yes. I think some of the people from PRIDE might have come down.

Brown: What was PRIDE?

Heumann: I don't remember what it stood for, but was run by a guy [Kurt Shamberg]. Ann Cupold would remember his name—and Ronnie, Ron Pagano, Ann's first husband. They were in Queens. They were smaller than we were. The guy who was the president wasn't disabled, but we did some stuff with them.

Brown: They weren't just a general disability organization?

Heumann: Yes, yes. We did work with EPVA [Eastern Paralyzed Veterans of America], Joe Mandela. Joe was great. He died. He was a very nice guy. We had meetings up there. There was another organization we belonged to. We were doing work with Eunice Fiorito because Eunice was the head of the Mayor's Committee. She had come in from Chicago. [pauses] I'm trying to remember these dates. In '72 something had gone on with Nixon already. I think he had already vetoed the bill once. That's when we went—and my parents with us. Did Jonathan talk to my mother about any of this stuff?

Participation of Heumann parents in Washington marches

Brown: About action? I don't recall. I don't think so.

Heumann: Too bad, because my mom and my dad drove down and helped us get around. Yes, they drove down. Yes, I'm pretty sure they did, both in '72 and '73.

Brown: Sorry, in New York?

Heumann: No, in Washington.

Brown: How did your parents feel about protesting and rallies and demonstrations?

Heumann: They were fine. They were not big on antiwar activities, but I don't think they really felt foreign about it because in their own right, that's what they had been doing years earlier. Just didn't have demonstrations. They had meetings. I don't ever remember there being any conflict. You were always supposed to be nice. Be nice. Which was my motto, be nice. Be nice until you couldn't be nice, but I figured I was nice, and I did that all the time.

Brown: Don't run over their feet.

Heumann: Exactly. You only do it if it warrants it. If being nice made them open a door, then you said, "Thank you." If it didn't, you slammed into 'em! With a smile, "Sorry."

Brown: [chuckling]

Heumann: What didn't I say that was clear? No, but that was always my—really, be nice.

Brown: Until that stops working, and then ram 'em.

— 186 —

Heumann: No, my parents were involved—I actually think in '72 we were definitely followed. I remember my father even saying something about how somebody was out there, taking pictures of the demonstrators. I've never looked up my FBI file. Maybe I don't have one, but I remember when my father said that. "There's people there taking pictures, not just newspaper reporters." I thought, well, that's kind of amazing; my father acknowledged that something like that could be going on.

1972 and 1973 Washington rallies

Heumann: When we had the demonstration in '72, where we had the rally to the Capitol, that was organized by us and a few other people. The one in '73 was a very big action. United Cerebral Palsy, Nancy Wesselman I want to say. Denise Jacobson would know her. I think Denise was actually doing work with Nancy then. They were very helpful. They put time and money into organizing that. Eunice's office was very involved.

I had met, through the President's Committee, people from different parts of the country and D.C. organizations, and so we were getting those organizations involved. People like Eunice were involved with groups like the American Council of the Blind. She was involved with some of the national groups. But in '72 it was a smaller group of us. I think the march that we had might have been a hundred people. It was us getting not just our people, but we were getting sympathizers from the President's Committee. There were thousands of people there, so you could pull off a few people.

Brown: Where was—the march went—

Heumann: From the Hilton, Connecticut Avenue, to the Capitol.

Brown: In '72.

Heumann: Yes, and '73. Seventy-two was the first one.

Brown: What did you do when you got to the Capitol?

Heumann: We had a press conference, and Senator [Harrison] Williams spoke. Ralf was helping us. Ralf was here. I think Ralf knew Lisa Walker, and I think that's how we first met. I'm pretty sure it was '72.

Brown: Did you speak at this press conference?

Heumann: At the rally? Probably.

Brown: I mean, you were president. You must have.

Heumann: Yes, I was president the whole time.

Brown: You were already speaking quite a bit and were very comfortable speaking in public?

Heumann: Oh, yes.

Brown: Did you prepare your speeches ahead of time at that point, or those were mostly off-the-cuff comments?

Heumann: I don't remember. Probably notes, but no, I didn't do written speeches, for sure. Kitty [Cone] was always the written speech person. I could never hold the paper up high enough to my face to be able to keep my eyes up, and I always thought it was terrible to keep your head down. That's from my singing. You never keep your head down. You always look out. My voice lessons really helped me a lot. My theater work that I did helped me a lot in everything I did because I was used to presenting.

Brown: And projecting.

Heumann: And projecting. I did plays since I was eight years old, and so that's really where I learned how to do that. I guess when I was younger, I'd be nervous looking out across a crowd and I cried [chuckling]. They used to call me Sarah Bernhardt. I did tell you that.

No, with DIA, we were definitely considered a militant organization. We were called, by some, communists, literally, which we used to laugh at.

Brown: Why?

Heumann: Because we were very strong in our actions, because we disrupted things, because we were not status quo people. We didn't just come to meetings. We yelled out at meetings, we spoke at meetings, we challenged people, and because they didn't know anybody like us before—at least in our generation.

Brown: Was that also a way of saying that they disagreed with you?

Heumann: It was a way of trying to discredit people.

Brown: Because if your communist—

Heumann: Because if you were a communist—. Right, and also people would say, Well, the system couldn't be so bad; look where you are now. You wouldn't have gotten here without the system. Of course, there was truth to that—not that the system was so good—but there was truth to the fact that there was something in the system that did let us go to college and various things. There was a system to work with, against, push, which is what we would say. But I remember hearing people say things like that. Basically, it was always a way of trying to minimize us.

On the other hand, I think I was asked to be on the board of the National Rehabilitation Association in '72 or '73, and it was in '72 that I met people from Rehab International, when I was at the President's Committee. That was a great place for networking. I think the traditional organizations were clearly seeing, from our activities and other groups, that they had to start looking at doing something differently.

Using the media

Heumann: The lawsuit really was the backdrop around much of this. There had been so much publicity around it that we were able to continue to get and we learned also how to use publicity. We weren't experts at it, but we did reasonably well for the time, to get coverage. Really, a lot of the coverage in the sixties and seventies was much more on the health page and the socialite page. We actually had a demonstration once outside *The New York Times*. We had a demonstration outside *The New York Times* around the time of the Nixon demonstrations, I believe, because they weren't giving us appropriate coverage, and people said, "You never demonstrate outside of a newspaper because then they'll never cover you."

We said, "Well, it didn't matter. They weren't covering us anyway. So the worst thing that would happen is they wouldn't cover us any more." But actually I think we had a meeting with them inside, as a result of the demonstration. It didn't make a dramatic change, but it did allow us to get in there and talk with them and explain what our concern was, that they weren't taking our issues seriously, like a civil rights issue, and that's what this was.

Roots of the civil rights model

Heumann: A lot of what we were talking about all the time was trying to elevate our effort from a medical model, charitable model to a civil rights model. Those of us who were activists had always been active in the disability rights movement. That's not what it was called years ago, but those of us who started—at least in these organizations—there were really no people who had become disabled later on in life. We were all people who had been disabled from birth or early on. That was a different type of person from us, a Kitty Cone or Paul Longmore or a Harlan Hahn or an Irv Zola, all of whom had been brought up in the nondisabled world. In some ways they had avoided—because they didn't see it—you could say, well, they didn't avoid it, but they did avoid it because there were things going on they didn't participate in.

Brown: Like?

"Born-again cripples"

Heumann: Well, they weren't, I don't think, involved with disability rights organizations. I don't think so—until like the seventies, eighties. As Kitty got more disabled, then she got more involved. That's not a criticism. I just think it's a statement of fact that they had disabilities that really allowed them, for various reasons, to be mingling more in the nondisabled world. They had a consciousness, I think, about stuff going on for them personally, but I don't call Kitty this, but I definitely call Paul and Irv and Harlan "born-again cripples."

— 189 —

I remember last year, when I was doing a lecture with Paul, and I called him a born-again cripple, he said, "What?!" I said, "It's true, you know." Again, it's not a bad thing. It's just that they were very well established in their professions and for whatever the reason was, now they took a more personal interest in it, and they were well established and they could do that.

The first time I ever remember really feeling that was when I was at one of the post-polio conferences in St. Louis. We had organized, with Ginny [Laurie], like, a discussion group. They had come to the meeting, and they were talking about a philosophy around disability. I remember sitting and talking to somebody next to me, going, They feel like they have invented all of this. This is stuff we had talked about ten years, twelve years, fifteen years earlier. But, because they were academicians—they had PhDs and they were men—but at any rate, yes, that was something we felt numbers of times. It's kind of the same level of things that still goes on today. It was, like, the women didn't have the same advantages.

So some of this stuff was very obvious. To talk about some of the more obvious forms of discrimination that were going on, those were things we definitely had talked about in DIA. That was really a time for us in DIA to really get together amongst ourselves, with an organization, that *was* supposed to be politically focused, as opposed to being in school or in camp, where you weren't there for that reason, although we did talk about those things. Here, it was an opportunity to talk about problems and reasons for problems. Really to begin to also look more at economic issues and the amount of money that was being spent in certain places and not here.

But then in '72 that's when I met people. I don't remember if I met Barbara Duncan in '71 or '72. The first time I traveled outside the United States was in '72. We used to have some of our DIA meetings, I think, at Bulova Watch School. Bulova Watch in Queens had a basketball team, wheelchair basketball team. We used to go out there sometimes for the wheelchair basketball games.

Foreign travel sparks awareness

Heumann: Then there was a group of them that were going over for the Para-Olympics. The Olympics were held in Munich, but the Para-Olympics were held in Heidelberg. They were held after the Olympics. I went with my brother Rickie and my friend, Pat Ford, and Teddy Mosier. Pat Ford is in Michigan now. We went to Germany, and then we went to Sweden, and then I came back on a Friday, and on a Saturday I left for Australia, to go to Rehabilitation International's World Assembly meeting.

Brown: In '72?

Heumann: Yes, because I left in '73, so it was definitely '72. I think so. But then I also had a six-week trip—

Brown: That was in '73, when you went to Norway and Sweden.

Heumann: Yes, before I went to Berkeley, yes. Anyway, in '72 going to Germany and going to Sweden—we haven't talked about that? Germany and Sweden were very important times for me. One, because going to Germany, I also visited my father's town and met some people who knew my father and actually visited outside the house that he had been born in and grown up in. I don't know where the pictures are from that.

At the games is when I first got to see lots of disabled people from all around the world. There were people there from eastern Europe, who came in wheelchairs that were just terrible. The European wheelchair companies and the U.S. wheelchair companies, I remember, were giving people wheelchairs, just so they had better equipment. But the games were great. I mean, it was very exciting. I do like sports, and I love wheelchair racing, and I love wheelchair basketball and activities like that. So it was a great opportunity to see all kinds of games going on with people from around the world but also, then, to talk to people about what it was like living in their country and what it was like living in the United States, and got talking about benefits.

Not that I went over there at all with an agenda to talk about what people got, but it was kind of a natural discussion. You start talking, "What's it like living in your country?" There were lots of people who spoke English, so we could talk to people from different countries who spoke English.

That's when I really began to see that there were other ways of doing business. We still, already, had a more civil rights approach, even though in '72 we didn't really have many pieces of civil rights legislation. But at the state level—in New York, for example—we did have pieces of legislation that dealt with architectural barriers. We did have the 1967 federal legislation on curb cuts and buildings. We were working on legislation. We were working at that point on the Rehab Act. Not so much, though.

But we were talking about what the problems were that we were facing and how we didn't have enough money for certain things and about how things were accessible and how we couldn't do things that we wanted to do. In our discussions about what we felt we needed, going into another two countries and seeing that while people were in similar situations, there were interesting differences. While one could define some of the differences being motivated around what some might call paternalism, they still had basic—I remember thinking they've still got a basic structure—where if the people were more aggressive, you could do more with what they had.

We had aggressive people without a lot to do with. Sweden in particular—I don't know how, but I started talking to people. We were there for a week, and they may have even had some places that we could visit to look at some programs.

Fokus Society

Brown: Like accessible housing?

Heumann: Yes, they had housing already then. They had Fokus. It's called the Fokus Society. The Fokus Society, I believe, they did it through a telethon and government money, and they

had accessible, somewhat integrated apartments, where people could live in their own apartments, and they had a unit where people would get their attendants from. Well, of course, that wasn't where we are today, but at that time there wasn't anything like that in the United States.

Brown: And those attendants were paid for?

Heumann: Yes.

Brown: And everyone in Sweden and Germany that needed it could get help?

Heumann: Now I'm just talking about Sweden, and I'm not talking about everybody. I don't know what they had overall, but I know they had some programs. Wolfensberger, who was big in the United States, actually, the Scandinavians say ripped off their ideas. There was stuff going on there in the fifties and sixties and seventies. So they were already, with their deinstitutionalization movement, and they did have services in the community. I don't know the full scope of the services, and they weren't like they are today, where they are more consumer controlled.

[Tape 14, Side A]

Heumann: I think—I'm not 100 percent sure—that the people were involved in the hiring in the Fokus units, but I believe they were involved. You could see that there were problems because people had to share attendants, and just having to share things meant that you couldn't do everything you wanted whenever you wanted to. But still, for me, who had nothing and had to use either my parents or people I had to rely on at school or my apartment, it was an interesting approach. I didn't feel completely comfortable with it, but I remember talking to people there and some of the social workers, and just thinking, Oh, my goodness, this is just amazing. Very different approach. Sweden economically at that point was better than it is today, so they were open to ideas. They had national organizations of disabled people, more than we did, and they were being supported by the government, which we, except for PVA, weren't—Paralyzed Veterans of America. And so it was all these different things.

National health care

Heumann: They had national health care, which they had in Germany. I knew a little bit about that. You heard about it, but you certainly didn't read articles in the newspaper on a regular basis, Let's look at the European health care system because maybe they provide better services. So it was coming back, and then I went to Australia. So within two months, I visited three countries. That was kind of an amazing experience. They were each different in their own right, even though two were European.

The Australian visit was—they were more [United States] U.S., Germany and Sweden—but nonetheless, they had a form of national health insurance also. So it really allowed me to begin to question and come back and talk to people in DIA and other places more about

the similarities and differences, and also to begin to see that there was this international movement.

More on DIA committee structure

Heumann: Anyway, so I think it was very helpful for me as I was doing my work in DIA. A lot of my work—I learn things and come back and try to do things with it. We were doing everything by the seat of our pants, as we still somewhat are—not as much—because now we've got laws and things. But as I was saying earlier, people have different interests. I think on a certain level it's see what different people are interested in and try to get people who might not have come out for A but would come out for B.

I think health care was one of the issues that we were dealing with. I think we had a health care committee. I think we had an employment committee, too. We had many more committees than people [chuckling]. We had lots of committees, and some people were involved a lot and some people were involved a little, as [in] any organization. But I think it was always incredible because we never had a lot of money. We didn't do fund-raising. I think we had dues but not a lot of money.

Brown: So who paid for you to go to D.C., when you all went to D.C. together?

Heumann: I think we paid ourselves, with our own money.

Brown: And registration?

Heumann: I don't think it cost anything to register to go to the President's Committee. It cost if you went to meals, if you went to the luncheon, if you went to the dinner. I don't remember when I started going to a couple of those, but people would just give me tickets.

Brown: Did you have an attendant that you paid? Or how did you deal with attendant stuff? Were there DIA members who could do attendant work for you?

Heumann: I was stronger at that time and thus able to be more independent. I would ask different people to help me. We shared hotel rooms at that time so getting help wasn't too hard. It might have just been whoever was there helping me out, without anybody in particular. Actually, Jan Balter—she's dead. She probably helped me on a number of occasions.

Brown: I was just curious if you had someone that was living with you and went on trips with you or if you found volunteers catch as catch can. Because your brother didn't help you when you went to Germany to the Para-Olympics.

Heumann: No, Teddy helped me then. When I went to Para-Olympics, Teddy helped me. My brother did help me, but not with the personal stuff, but he helped with pushing my wheelchair and all that kind of stuff.

Brown: You took your manual, too?

Heumann: Yes. Well, I'm not sure, but I think I only took my manual chair.

Brown: Do you remember having any problems on the plane?

Heumann: Oh, no, we had no problems because, remember, we went with the wheelchair team.

Brown: Oh, right.

Heumann: We had no problems because they were a-scared of us. They had all these strong guys that carried us on and off the plane. We didn't even use aisle chairs because it was the trainers and staff that put us on and off. I do remember that. That was fun. That was great, being around all these disabled men. It was so exciting. It was great. I had never—well—I had, when I was at basketball games and things like that, and at camp. But this was, like, amazing. This was like a candy store. They were everywhere. I had never been at a place where there were so many disabled people.

DIA chapters in Baltimore and Philadelphia

Heumann: DIA, I think, for me was a very important part of my life. Again, it was something that a group of us created. It was similar to what CIL was doing, although they grew out of DSP. I left college in '69, and we were just starting the Disabled Students Program at LIU [Long Island University], and at PDSP they clearly were thinking about what they needed to do to make life easier for the students. It probably was a combination of them moving from Cowell Hospital into the community and needing different types of supports.

But we weren't there yet. Because we weren't looking at money. We hadn't been involved with any organizations that really did fund-raising. We kind of knew that it was something that you did, but when we thought about fund-raising, it was more what we knew, it was dues. Grant writing wasn't something that we knew about at that point, because all of us who worked had regular jobs. Like, Denise worked in a law firm; they didn't do fund-raising. I worked for a school system; they didn't do fund-raising. So we didn't know about it.

I think we did a lot with a little. There were a couple of other chapters of DIA that were forming. There was one in Baltimore, Bob Ardinger, who lives down here now, whose wife is the deaf woman at HUD, whose name I'm forgetting, Cheryl. But Bob started DIA down here. I actually remember coming down here to talk at a meeting they were holding to start the DIA chapter down here.

Brown: In D.C.

Heumann: Baltimore area, I think. Not in D.C. I don't know if Philadelphia started after I left. But it is interesting to see that DIA hasn't really gotten much bigger, but it's still there. Can't say that about a lot of other organizations, so there was something good about it. A lot of the people who worked in it at the beginning aren't really involved. There's a whole new group of people. But they're involved in lawsuits, and they're involved in many different activities in a similar vein to what we were doing at that time.

The core people at DIA went to work in independent living centers, a lot. Denise did, I did, Bobbi Linn did, Pat Figueroa did. When did Pat go on the board? Do you remember? Seventy-two, '73 maybe. So many of us moved there. DIA continued to do its community—and there were some struggles that went on over time between DIA and some of those organizations. I don't know if the personalities of the people involved were copasetic—would that be the right word? But there were tensions, styles of people.

But nonetheless, I think Frieda [Tankus] has been involved with them for many years now. We did so many different things. I think the Nixon demonstrations—we haven't talked about those?

DIA Nixon demonstrations in Manhattan

Brown: No, we could talk about specific demonstrations, if you want.

Heumann: Well, the Nixon demonstration was great.

Brown: Which ones in particular?

Heumann: All of them. They were kind of a package deal. We didn't plan two and three; we planned one. God, I thought I discussed this. I've been talking to too many people lately. But the demonstration on the second, I guess it was, Thursday?

[going through papers]

Brown: That one?

Heumann: Yes, these two. Okay. This is how these came about. The first article is "Disabled Tie Up Traffic Here to Protest Nixon Aid, Hill Vote Friday, November 3rd."

Brown: And that's from *The Times*.

Heumann: *The New York Times*. What actually happened here is PRIDE and DIA organized a demonstration. I believe Nixon had vetoed the act—

Brown: The Rehab [Rehabilitation Act of 1973] Act.

Heumann: The Rehab Act. There were many provisions in there that we felt were important. There was an independent living provision. We hadn't been involved really in the development of much of this stuff, but we heard about what was going on through contacts that we had in D.C. There is Jim Ford, Pat Payne's husband. And there's Ronnie Pagano. At any rate, Ronnie was a pretty creative guy, from PRIDE. I think the way we looked at doing a lot of our activities was we wanted them to be informational. We didn't want to just have demonstrations. If we were going to have them, we wanted fliers, we wanted things that you could give to people that they could understand. We were convinced that if people understood what the issues are, they'd be more supportive of the issues.

We decided that we would have this demonstration outside of the federal building in Manhattan. We never, I think, sent anybody up there to actually scout out where the federal building was. We decided that we would get a coffin, and we would dress and act as though we were having a funeral. We had fliers, thousands of fliers, that were actually [shaped like a] tombstone, and talked about Nixon killing the Rehab Act and writing on the tombstone what the specific provisions were that were not going to be enacted.

So we get up to the federal building, and it turns out that the federal building is the only building in all of New York City which is on a little island, where no traffic ever comes. It was totally bizarre. I don't remember where it was, but it was totally bizarre. We had this demonstration outside, on the sidewalk. Nobody really cared, you know. They sent somebody outside. We talked to the people.

Brown: There weren't any cars going by.

Heumann: Well, we were on the sidewalk. There were cars, but very few cars. I don't know if we were asked to go inside. Whatever, we had a little bit of press, but it was kind of a non-event. I thought we worked so hard on this, we cannot have this be a non-event, so we went in the street. The cops came. The cops had been there. What happened? Well, they didn't want us to be there, even though it was on the sidewalk, at first. Someone came out and asked who was in charge, and people said I was, and they came over, and "You're in charge. You have to move." I said, "We're not going to move." They said, "Okay." They left.

Brown: [laughing]

Heumann: There we were. We looked great, sounded great, had all the right stuff, and nobody cared that we were there. So then we went into the street. Nobody really cared much more that we were there because I think people could either go to another street or whatever, but it was having zero effect on anything. So we're sitting around. My God, what are we going to do now? The police were there, and they helped us. They said, "You should leave." We're, like, can't leave.

So then we asked one of the cops, "Where is Nixon headquarters?" So they called in and asked. I think they were told, "Get 'em out of my precinct!" So where's Nixon headquarters? They come back and tell us. So we all got in whatever we had gotten to get there, and we decide we're going to go up to Nixon headquarters, and there we are, and decide, okay, we'll take over the street. It was totally unorganized. But we still had our fliers. We had more fliers printed. We had thousands of fliers. This [showing] is it.

Madison Avenue takeover

Heumann: Actually, we were also working with the Willowbrook people. Of course, there were now real communists in the group, and they had a lot more experience than we did. But I think everybody was blown away. I'm, like, "Let's go in the street." So we actually took over Madison Avenue, and the two other streets, so we actually had shut down three streets. But some of the trucks were not happy having three streets shut down on them, so we

decided we'd go back to one street because we thought it could be pretty bloody, so we just went across Madison Avenue. We stayed there. It was, like 4:45 in the afternoon by the time we got there, 4:30. Yes, Madison and 45th Street.

No one knew we were coming, so no one knew why we were there. Someone came out and said, "What do you want?" We said, "We want to talk to somebody from Nixon headquarters." So they sent somebody out from Nixon headquarters. "What do you want?" "We want a public debate with the President on why he vetoed the Rehabilitation Act on MacNeil Lehrer" [News Hour on PBS] or something like that. They're, like, "You're crazy." I said, "That's what we want. That's why we're here."

We must have stayed there an hour. We really did shut the city down. But we had hardly any press. It was really terrible. If it would have been any other group, A) they wouldn't have let them sit there for an hour in the afternoon, and B) it would have been all over the media. Anyway, after we stayed there for about an hour and had done what we wanted to do, we went into Nixon headquarters. We went in, and we took over the floor. It was kind of like cripples threw the Nixon people off guard. They didn't know what to do.

We were there, and we were chanting, and we were having these demonstrations, and it's four days before the election, and it's at Nixon headquarters. The police were there, but it turned out we had these really nice cops, who were not into doing anything to us because in this particular precinct, there had been a couple of cops who had been shot in the last year, and so some of the guys that we were dealing with had actually been involved in helping to get their friends to therapy at different places, and they totally understood what we were talking about: lack of transportation, dah-dah-dah-dah-dah-dah. About midnight, we left. A little after midnight.

Second demonstration with Vietnam vets in Times Square

Heumann: We were upset. We didn't get the coverage that we wanted to get. Some people said we didn't get coverage because we didn't have any Vietnam vets with us. So I called a woman named Nancy Amaday. I didn't know Nancy Amaday from a hole in the wall. I called [George] McGovern headquarters and said—their position, of course, was the right position—and we were supporting McGovern. Not really active in the campaign, but I explained what had happened, and I said, "We want to have another demonstration on Monday. We need some vets."

That's how Bobby Muller got involved.

Brown: Who?

Heumann: Bobby Muller. He runs Vietnam Vets of America. He's one of the guys who won or, I think, was a co-winner of the Nobel Peace Prize with this woman from Vermont, two years ago, on the land mine issue. Anyway, he was a big Vietnam vet, very well, known in the Vietnam vet community. She sent him. Bobby Muller and I think one or two other guys. I don't know who they were. I never saw them again.

We had decided that this time, we were going to meet on Times Square and we were going to march against traffic up Times Square. I remember Bobby, if you talk to him, he will talk to you about how he thought this was the craziest thing he'd ever seen or done in his entire life, and he talked to people about how crazy I was, how I was more out there than he was, and Pat Figueroa and all of us. Pat Figueroa said he was a Vietnam vet. Sure, who knew the difference? So he said he lost his legs in Vietnam. Nobody ever asked him, "Where did you see combat? What division were you in?" So he was our artificial Vietnam vet until Bobby and the others came along.

So then we marched up Times Square, shut down traffic again. It was earlier in the day this time. This time we had a lot of press, so there are more articles [leafing through them]. Do you have them? There are definitely more articles because we had the vets. This [showing] was Monday. This was Thursday; this was the next Monday.

Brown: November 6.

Heumann: Right. Sorry, this was *bupkes* [Yiddish word meaning nothing, peanuts] coverage that we got in *The New York Times*, but it was page three. No, this was the *New York Post.* This was the *New York Post*, page three, November 7th. It was a good picture. No, this was another time. But now we had more people. The first one, on that Thursday, I think we had fifty people, and a lot of them were from whatever the group was called from Willowbrook. That was very helpful.

Then, again, you know, we went into Nixon headquarters. This time, we did shut Nixon headquarters down the day before the election. They called in a bomb threat. God, I remember all these things happening. We still wanted to debate the President—

Brown: Who called in a bomb threat?

Heumann: I have no idea, but there was a bomb threat called in. We thought, "Nobody's leaving, so if nobody's leaving, why are we going to leave? It's probably not a real bomb threat." So we said, "Thanks, but we're not going to go." A little nervous for a couple of minutes, waiting for the bomb to go off. But there was stuff that was going on, things that were happening.

I think this is Jan Balter, actually, right there. This is Neil Jacobson, I think. Is this Neil? No. Kip Watson. That's Kip Watson. Where's Bobby? Was that me with the megaphone in front of my face? That's Bobby Muller right there, yes.

At any rate, they were pretty amazing. Those demonstrations were the first big ones before we had the all-night vigil—this was '72, I guess, right? In November. Then it was '73 in the spring that we had this much bigger demonstration in D.C., which I think had more like five hundred people. That's the one that UCP [United Cerebral Palsy] and all the others worked on. There, there were busloads of people that were brought in because people had money to do something. Here, for these demonstrations, we even got the van services to donate. We'd call and say, "Look, If you get us there, maybe it will mean we'll get more money, and that'll help you out." We did everything. We had no money.

But the demonstrations against Nixon were very exciting. We gave out thousands and thousands of fliers. What I really remembered about the fliers was that you didn't see a lot of them on the ground. People took them with them because they were interesting and

because the people that were giving them out were trying to explain—although in New York, you know, you can't give much of an explanation on Madison and Times Square as things are coming and going—but there wasn't a lot of hostility. A little bit. There was one or two cars that did scream against us and stuff, but as a rule, we had a lot more coverage the second time, as I recall, radio and TV coverage. It was a very exciting time because we realized that we really could do more and more things to get the messages out. So that was very exciting.

Then, when we organized the '73 demonstration, the big '73 demonstration with those other organizations, did a lot of work on that. We got a lot of people down there, but there were a lot more people from other organizations. There was the march again.

Disrupting Julie Nixon Eisenhower's speech, 1973

Brown: Can you say a little bit about just what actually happened?

Heumann: At the '73 demonstration?

Brown: Is that the one that started with disrupting Julie [Nixon] Eisenhower's speech?

Heumann: I guess so.

Brown: Do you remember that?

Heumann: I remember disrupting Julie Eisenhower's speech, and I remember that it was before a march. I don't remember that it was before this particular one. For some reason, I want to say that it was in '72 that we disrupted her speech. At that one, she was saying garbage.

Brown: Was it pre-planned?

Heumann: The disruption? Probably, because we had posters hidden.

Brown: I guess it would have been pre-planned!

Heumann: I don't know how much we were intending on disrupting it. We probably were intending on walking out against her.

Brown: Was it because—

Heumann: Because Nixon wasn't doing stuff that we needed, and it was a forum. I mean, again, it was our stage. We didn't have the money to organize something like that that we could make a protest at.

Brown: Was she on the President's Committee?

Heumann: Her father was in charge of it. It's all titular, you know?

Brown: Right, right.

Heumann: It's the President's Committee, but how involved is the President in the President's Committee?

Brown: Right. So she was giving comments, and she was saying garbage. Then what happened?

Heumann: We started yelling out. People went, "Shhh! Shhh!" We were yelling out stuff about her father and why he vetoed the act. You know, different things like that. Then we picked up our posters and left, chanting.

Brown: What were you chanting?

Heumann: I don't remember what we were chanting, but whatever it was, they had never seen anything like that before at the President's Committee meeting [chuckling], and never again. Really, after we stopped doing it, it went back to its regular meeting kind of stuff. So we gave them three years of a little bit of excitement [chuckling].

Brown: So you left chanting, and then you went—

Heumann: As I said, I can't remember whether the Julie Eisenhower walk-out. If I were to bet, I'd bet it was in '72 because in '73 there was this other very organized demonstration, and we probably wouldn't have done that. But, of course, I could be wrong. Does it say we did that?

Brown: It does.

Heumann: In '73?

Brown: [reading]: "On May 4th, '73, there was an annual gathering of about thirty-five hundred people at the Hilton. About thirty persons, many in wheelchairs, left the room during remarks by Julie Nixon Eisenhower, who presented awards on behalf of the President's Committee."

Heumann: Okay. So maybe we only did it in '73.

Brown: Maybe the paper is wrong.

Heumann: No, the paper wouldn't be wrong.

Brown: So then you left her speech and went—you marched right from the Hilton?

Vigil at the Lincoln Memorial

Heumann: That's where the marchers went from.

Brown: And you went to?

Heumann: I'm looking at the article.

Brown: I mean, did you go right to the vigil?

Heumann: I don't remember the timing. The vigil was in the evening, so we would have done the march, gone to the Hill, and then gone to the vigil.

Brown: The vigil, you're saying, was the one that was organized with other groups and was quite large?

Heumann: Right, right. That's the one that United Cerebral Palsy—see, they are listed here, too. [Reading]: "The group, comprised mainly of persons attending the annual meetings here of the President's

Committee and United Cerebral Palsy—" I don't know that United Cerebral Palsy had their annual meeting at that time. I don't remember.

[Tape 14, Side B]

Heumann: I believe what these articles show—you know, the demonstrations against Nixon headquarters in '72 and the articles of May '73, with the protests at the Hilton during the President's Committee meeting, and the vigil at the Lincoln Memorial, and subsequent march from the Lincoln Memorial to the Capitol—we were getting better coverage. We were not on the front section of the *Post* ; it was C-2, so that must have been Metro [the metropolitan section], when it wasn't a metro story; it was a national story.

Learning about Center for Independent Living at Berkeley

Heumann: But we also were coming into our own. The articles weren't exactly right because DIA organized it, though, as I say, we weren't the only organizers. It was our way of beginning to work more on the national level. It was the Lincoln Memorial vigil which was the first time that I met any people from CIL [Center for Independent Living] and Berkeley. Larry Biscamp and Dick Santos were there. That was the first time I ever heard of CIL.

Brown: You met them and they said they worked for CIL in Berkeley, and you said, "What's that?"

Heumann: Oh, yes. No one knew what it was.

Brown: Did it sound impressive? Interesting? Just was another program?

Heumann: It sounded interesting.

Brown: Different?

Heumann: It was different because it was doing political activism linked with services, which we hadn't done.

Brown: Had anybody been doing that, that you know of?

Heumann: No, no. Except for programs like U of I [University of Illinois at Champaign-Urbana], University of Missouri at Columbia, where they did have some services, but the U of I's was very sports-oriented. They didn't have real support services as I knew it, from what I heard from friends. It was more you had to kind of do it on your own. What they were talking about—Larry and Dick were talking about—was interesting. But none of us had ever heard about it, and God knows when we would have ever heard about CIL again had Ed [Edward V. Roberts] not called for me to get involved because they were not at all seen as national players, no.

Multiple group sponsorship

Brown: Do you want to talk any more about your personal experience of any of these events? I'd be very interested in hearing how the vigil went for you. What you thought about it, what happened.

Heumann: I think all these events to me were very powerful events. They were fun events because there were a lot of us together. We got to talk to each other and meet new people. We got to see how our organizing really could pay off because people did come. We got to talk to some media, which always was important. I think we always kind of joked about how much work we had to do to get such few people, and that was something that we thought a lot about. See, we always were under-counted, but still, I really thought we had about five hundred people between the vigil and the march, but I don't know. Nancy would remember, probably better. As I said, I think Denise knows where to reach her.

Brown: Do you remember the structure of the vigil? What happened? What your role in it was?

Heumann: We had singing. I was one of the organizers of it.

Brown: Were people giving little political speeches?

Heumann: Yes, there were speeches that were given. We stayed out all night. People slept outside. I had to get permits and there was all that stuff, because you had to do that. I think Eunice's office and Nancy and others—I mean, there was a good group of people that had organized this. That's why Durwood McDaniel, who was with the American Council of the Blind—in this article—because Eunice was very active with them. There were mainly people in wheelchairs at the demonstrations, but there were lots of other people, too, which was the first time that, to our knowledge, that that had happened. There were some deaf people, and there were blind people and physically disabled people and civilians and veterans and some parents. It was a broader cross-section of people than had existed before. So we were [sound of screeching brakes outside, then a honking horn]—Oh, God. That's Connecticut Avenue.

We were beginning to see that the message had an interest, and members of the Hill were interested. I believe we did do some lobbying. This other article that I read—was that around this one, or the other one? Yes. Was this around—what's the date of that?

Brown: I think this is in April of '73.

Heumann: Okay.

Brown: It sounds like you made a special trip at some point.

Heumann: To go down there.

Brown: To visit Congress in '73, in April.

Heumann: Yes. At any rate, we didn't like Nixon. He was a great target. We were slowly getting the message out and slowly having an impact on some of the traditional organizations. I mean, UCP putting time and money into organizing this vigil, was pretty momentous. They definitely were not involved in the walk-out. No doubt about that. But they did give time and money and personnel. I do believe they paid Denise to work on this, and I do believe that Nancy from UCP, who wasn't disabled—I think she ran a youth program—and she was very involved in this. They gave a lot of her time to this. She was out of the New York office. So I think that was all very important.

Anything else?

Brown: Well, I was just wondering what your experience was at any of these events. It's interesting to hear the anecdotes that pop out. Did anybody catch on fire?

Heumann: No, no.

Cross-disability component

Brown: But you said that the vigil was the first one you could remember having a real strong cross-disability component?

Heumann: Well, yes, because that was the first demonstration that was organized to do that. I think both PRIDE and DIA in New York were more cross-disability than most other groups, and because we were working with this group around Willowbrook, we had parents involved that hadn't been involved before. There weren't really individuals who themselves had cognitive disabilities who were very involved, but there were some. DIA was primarily an organization of physically disabled people. But even on that it was cross because usually it was the UCP group and the muscular dystrophy group and the March of Dimes group. So even though people looked like they had similar disabilities, it was the beginning of a cross-disability because we had different types of disabilities. That, in and of itself, was different still, at that time.

But anecdotes. I mean, I just remember that it was a real high, being at the Memorial, being in the marches, meeting with people, seeing people there. That it was a good feeling for us to be talking proactively about not just the problems but what we wanted. It was a time that we began to meet with some of the staff on the Hill who, of course, were working on these things, and we weren't really working on it. It was the paid lobbyists that were working on this stuff. We weren't very involved in it. But I think we also helped what was going on with the Rehab Act. We didn't really get involved in IDEA [Individuals with Disabilities Education Act]. We didn't really know about it.

Of course, one of the reasons why we were very much in support of the '72 act was because of the civil rights provisions. It wasn't just the independent living provisions. It was Title V. That was a very big deal for us because we really saw that as a critical part of the legislation, to help deal with discrimination issues. Yes, I'm sure the fact that the Lincoln Memorial was a federal building meant that this would have an impact on it. So there was a lot of symbolism going on, a lot of first times for people to be at a national demonstration. For some, it was the first time they had ever been in a demonstration.

The thirty people who walked out on Julie Nixon—that was a big deal. You don't demonstrate against the President's daughter. So it was all these things that were happening, that we were trying and doing, and the world didn't fall apart, and we made a point. I think we felt good about what we were doing. As I said, there were some who thought what we were doing was terrible, and others who were very happy that we were doing it. Some who joined us, and some who were afraid to join us and kind of looked on the sideline.

But that was really, I think, in those periods of time that we began to push an agenda that said, "Where are the disabled people? Why are these organizations not hiring disabled people, using disabled people in positions of responsibility?" It was from those activities that I actually got my job working in D.C.

Brown: The internship?

Heumann: Well, it wasn't really an internship. It was a full-time, paid position. I wasn't considered an intern. I went there to do a residency.

Brown: That's what I meant, residency.

Heumann: Right. But it wasn't a special job. In other words, they had a job opening for an L.A., legislative assistant. They had, like, 130-some applicants, and I got the job, so I did it for my university requirement, but I was a regular employee, paid a regular salary.

Brown: That's what I meant by intern. That's all I meant, was that you were getting school credit for it.

Heumann: Right.

Background on President's Committee

Brown: I have some questions I just wanted to go back to or ask. Was the President's Committee at this point, when you were attending, was it primarily nondisabled people that were involved? Or just they were all more conservative or traditional people?

Heumann: It was and is still primarily nondisabled people, although there were numbers of disabled people who went there. The President's Committee started in '47 or '49, as a result of the Second World War. They had affiliates in many states. The affiliates were Governor's Committees. The Governor's Committees had disabled people on them. So that's where some of the disabled people came from. They were either executive directors of the Governor's Committees or they were on the Governor's Committees. There were some disabled people that were on the President's Committee, advisory committee, but I don't think that many, really. People from D.C. came, from different organizations, but it was primarily nondisabled people from business and provider organizations.

The "militant" label

Brown: Then I wanted to go back to the issue of "militant" because I did see it in a number of the articles that I read. Was that another way that people were trying to minimize what it was that you were doing? I mean, what was the issue?

Heumann: If the word "militant" turns you off, it did; if the word "militant" didn't—you know what I mean? It just depended on what the reader thought about the word "militant." "Militant" was, I assume, because we were very vocal in our opposition, and we weren't traditional in our opposition. We were vocal about it, we had posters about it, we gave out fliers about it, we broke up meetings about it, we demonstrated about it. Really, remember the time. It was during the Vietnam War, and there were a lot of activities going on. They were not as militant as some of the other activities, but for the way people had thought about disabled people, they were very militant.

They were. We were doing the most kind of aggressive activities. There was nobody else doing what we were doing at that time. They were much more like things are now.

Brown: In one of the articles, I remember specifically it was an interview situation, and someone brought up the word "militant," and your answer seemed a little bit defensive, and I was wondering if that was just because—

Heumann: What was the answer?

Brown: I think you were saying basically these issues are really, really important, and we see ourselves more as being assertive and saying, "This really has to change."

Heumann: Right.

Brown: I thought that was a fine answer, but there were elements of defensiveness, and I was wondering if that just came from feeling that that was an attempt to dismiss, based on using that term.

Heumann: I don't know that it would have been defensive. I don't know that I would have felt defensive about it. Rather, it would have been an explanation, why are you? My response probably would have been using the word "militant," whoever was using it was trying to discredit what we were doing, so it was to try to say, "Don't discredit what we're doing

because we're not following the kind of mentality of being thankful for whatever we were getting."

Because that's what this was all about, was really saying that we weren't thankful for what we weren't getting. We wanted people to have a better understanding that we were doing these things in the way we were doing them because in the traditional way, nobody had listened to us. So it really was a way of getting people's attention, was one of the reasons why we were doing these things. You know, you tried to get a meeting, you tried to have a regular discussion, and nothing seemed to change. This was a way of at least getting some people to look at these issues in a way that they weren't willing to look at before. That was, for some people, militant, communist, whatever they wanted to call it.

Using demonstrations as a message medium

Heumann: We definitely talked about DIA and what was going on as a civil rights movement. We did not use terms like independent living because that just was something that came out of CIL. We didn't know about CIL. I think the term "independent living movement" was not used really in '72, '73. I think it was more '74, '75, '76, '77 that those words began to be more popular. But we definitely talked about the charitable model versus the civil rights. I don't think we used the word "model." It was more like charity versus civil rights, human rights, civil rights. I think we probably used those phrases, from charity to civil rights, more.

I think also, for me, the DIA days—there were apparently demonstrations that took place in the thirties, and there were other activities that had gone on earlier, like the formation of the National Association of the Deaf, and guilds as early as the 1500s that I read about—but at that age and without any historians really involved with us, it felt very much like we were creating something new, which I do believe is true. It was something new. But the demonstrations that went on in the thirties were also probably something new for the time.

I think what's important about what's going on now is that there is more of a documentation of what's happening and hopefully that we can talk and reflect about the history so that every time we do something it doesn't feel new. The model that we started—well, the model that we used, I don't want to say started—the model that we used in DIA was later on something I learned about that was going on in California with CIL. Although they were using the courts more than we were, because they were aligned with more of the civil rights groups.

There were definitely court actions that were going on in New York and the area that we were involved with directly, like my education case—also the Willowbrook case—Joe Mandela and the guys from EPVA were probably involved in some litigation dealing with accessibility-related issues. But DIA as a rule, to the best of my recollection, was not named during the three years that I was there in any litigation, although it certainly has been since then—numbers of pieces of litigation.

— 206 —

I think in the seventies when I went out to CIL—and I know we're not discussing CIL now—but, again, we used demonstrations as a mechanism for getting a message out and organizing, community organizing. Then when ADAPT [American Disabled for Accessible Public Transit; American Disabled for Attendant Programs Today] came out in the eighties—I think that came about in the early eighties—they also were building on that model and I think were more aggressive in what they were doing, which was appropriate, and is appropriate.

Brown: You said "and is appropriate," right?

Heumann: Yes. That model is one that hasn't been abandoned; it has just been built on. In many ways, the disability community has been continuing to use that model, I think, in a more aggressive way than at least you read about for other groups, others have big marches, with thousands and thousands of people. We never have been able yet to get to the thousands and thousands of people march, so maybe the way to get attention when you've only got a couple of hundred people is to have to be more aggressive in your approach. I don't know, but anyway, I think it's a very effective tool and one that does sometimes get some attention.

UN Plaza Rally

Brown: I was wondering if you wanted to talk at all, to say anything else about the UN Plaza rally or protest that you had. I think there were actually two different protests that you had.

Heumann: What were they about? I remember one because I remember—well, I think—who knows what I remember.

Brown: [going through papers] This was just a demand for equal rights. It was part of the national civil rights groups for the disabled. This was in 1972, Monday, May 8th. This article was from the *Daily News*.

Heumann: Let me see it.

Brown: That was the one that Eleanor Holmes Norton and all of them were at.

Heumann: [silently reading the article] I remember going to this. I remember that—what's the date?

Brown: May 8 of '72.

Heumann: And when was the demonstrations at the President's Committee?

Brown: That was—

Heumann: In '72.

Brown: I didn't have any articles about '72. I wasn't even sure that you went to the President's Committee in '72 because I didn't have anything written down.

— 207 —

Heumann: But, see, I think if you look in '73, I believe that this demonstration came about—it was organized—I mean, it wasn't one that just happened. But we did bring people from the

President's Committee up because I do remember Charlie somebody or other, who came from New Mexico [whispers something inaudible]—

Brown: [chuckling]

Heumann: —and came up to New York. I remember a group of us sleeping in my mother's living room before we went to the rally. I'm trying to remember who organized it. We were involved. I don't know. Maybe the newsletter would—but clearly, it was a more organized one because all these people spoke.

Brown: Politicians.

Heumann: Right. Again, looking at the picture, it was one of our large but not overwhelming demonstrations. I do remember it, though. I remember it happening, and I remember—that's Jimmy there. I have to look at the newsletter and talk to somebody.

Brown: Okay, that's fine.

Demonstrations as communication

Heumann: But, again, it was in that time also a mode of communication. Demonstrations were not uncommon. I think Adrienne Asch—I don't remember if she was on the Human Rights Commission that filed a complaint. I don't remember. But she was involved with some stuff around that.

Brown: All right. Well, two other things. What role did your experiences with DIA have on your approach to the world of activism later on?

Heumann: It definitely is something that I think I continued to use. As I said earlier, it was a combination of trying to be analytical about what the problem was, what the solution was. We weren't as locked into the legislative mode as we are now, although we did work on bills in the city and at the state level. Then did work progressively—as the years went by—we worked more on federal legislation so that demonstrations against the Nixon vetoing, while we weren't very involved in the writing of it, we were involved with at least making statements about the importance of it.

So I think it's something that to this day is very important. You need a comprehensive approach, and I think it is important to have people who are willing—I don't know why demonstrations in and of themselves sometimes make people very nervous. From my perspective, maybe it's because I believe in them and have done so many of them that I just see them as part of a continuum.

I don't think it's a good idea in demonstrations to be violent or unduly disruptive. Some things that I hear about sometimes, I don't necessarily think is the best way of doing things. But I think civil disobedience is important. I think there also is an issue of personal commitment. If someone is involved in a demonstration and the demonstration leads more to the possibility of people being arrested, I think there is something—if it's not being done in a cavalier way and a stupid way—that's important because you're making a political statement. It's a personal statement, even before it's a political statement, that you're willing to risk in order to fight for something you believe in.

Do I believe that that's what people should do the first thing is go out and block traffic? No. But do I believe that it's an important part of what goes on? Yes.

Final thoughts on DIA

Brown: My last question is, given that hindsight is often 20:20 vision, is there anything that you would do differently or that you wished DIA had done differently regarding those years and the activism that you did?

Heumann: No, I don't think about it. There are other things that I've done that I think about that way, but we didn't really know a lot. If everything was as it was, could we have done things much differently? No, I don't really think so. We were a new group of people that didn't know each other, that were coming together, that didn't have a lot of community organizing background. We weren't, as I said, a part of, as a rule, other political organizations, where we could have learned things. I think we worked full-time, dealing with our disabilities, and dealing with this organization, so I think, given everything, we did kind of a phenomenal job.

Really, we were kind of out there. It was like looking and learning from what other people seemed to be doing, and expanding on it from our perspective of disability. I think our intent was to educate people, the general populous, and to educate disabled people and to educate policy makers and legislators. I think, given the size of who we were, there was a lot of smoke and mirrors going on. But people really believed it, and so we definitely put the smoke in the mirror, as many mirrors and as much smoke as we could. I mean, considering everything, we did a pretty good job.

When I left and I came to California because I was in graduate school, I didn't have a lot of contact with the organization anymore. It was kind of an abrupt, almost, ending. Of course, I was still friends with people like Bobbi Linn and Denise McQuade and Pat Figueroa and Pat Ford. But numbers of people then started moving on and out to other organizations, so the new leadership I didn't really know. I mean, I know some of them now because they invited us back, which I think was to the credit of the people that were and are still working on DIA, that they see it from a historical perspective, and people felt it was important who the founders were.

I think that was good, but I don't think—I could look at things at CIL and say, Well, too bad we didn't do things this way or that way, but I think then I didn't know a lot of other options. We didn't know a lot of other options.

Brown: Anything else you want to say about DIA before we close?

Heumann: I just think it was a very important organization, not just for us but for others. I also think that it gave a lot of us opportunities to learn and then to move into more structured organizations. Yes.

Brown: Okay.

[tape interruption]

Brown: Do you want to say a little bit about what your duties were as president?

Heumann: It was a very significantly women-oriented organization, we tended to do everything in groups. I guess I would chair meetings. My job was to be one of the leaders of the organization, to try to make sure that things were getting done in a timely way. But people like Denise Figueroa and our mothers—my mother, Denise's mother, Frieda Tankus, Jimmy, Larry—all these people—there wouldn't have been a DIA without all these people.

I think that I was one of the people who felt comfortable as a spokesperson, so I, in this capacity, would more often than not be seen as the person to send people to at rallies and demonstrations, to make statements. I'd be a person who would make statements at rallies.

Judy Heumann, circa 1980 *Photo by Betty Medsger*

Judy Heumann, circa 1980 *Photo by Betty Medsger*

Ed Roberts, Joan Leon, and Judy Heumann, founders of the World Institute on Disability, 1984 *Photo by Andrew Ritchie*

Bill Clinton and Judy Heumann, December 1998

X. A Summer of International Travel and a Year as a Graduate Student in Public Health, 1973-1974

Travel in Europe for Rehabilitation International

[Interview 10: March 13, 1999] [Tape 15, Side A]

Brown: In the summer of 1973 you traveled in Europe as a consultant for the International Society for the Rehabilitation of the Disabled. If you could tell me just a little bit more about the organization, where they're based, and what they do.

Heumann: It's now called Rehabilitation International. It's based in New York City, Manhattan. You've been there. They're an international organization. They have chapters all over the world. They had been a mainly nondisabled organization, and in the seventies, as the disability movement was getting stronger, they began to look at ways that they could get more influence by disabled younger people.

I had met Norman Acton and Barbara Duncan, I guess it was in 1972 or so. There was this youth program being held in Finland. You had to be twenty-five or younger, and I was just twenty-five. I guess I was twenty-five and a half. They asked me if I would be interested in going, and I went with another friend of mine, Jan Balter.

Brown: When was this?

Heumann: Seventy-three. We were away for six weeks. We were in Norway, Sweden, Scotland, and England.

Brown: You already knew about them before you were a consultant for them.

Heumann: Right, yes, I had met them before.

Brown: So they basically asked, "Do you want to go to Europe?" So what was the purpose of your trip? I mean, were you working for them? Were you getting paid?

Heumann: I didn't get a salary, but they paid for the trip.

Brown: They paid for your expenses. Did you take an attendant with you?

Heumann: Jan Balter.

Brown: Oh, she was your attendant.

Heumann: She was disabled also.

Brown: So they paid both of you.

Heumann: I think so, yes.

Brown: What was the purpose of the trip?

Heumann: It was basically to—and I really remember the Norwegian part, the Swedish [sic; Scotland] part, and the English part. I don't remember that much about the Swedish—I guess because I've been in Sweden so many times and I've only been to Scotland and Norway once, so I remember that more. The English trip was bizarre.

The Norway trip, which was the primary reason to go, was that there was an International Red Cross youth camp in Norway, so Jan and I were the two U.S. representatives. There were people there from Africa, Europe, Scandinavia. There was a woman there from Spain and a guy there from Denmark. That's where I met Kalle Konkkola.

Brown: I was going to ask that. I'll cross that question off.

Heumann: Yes. I think we were there for about ten days.

Brown: At the camp.

Heumann: Yes.

Brown: You said you were gone for six weeks. So ten days was in Norway, and the rest of it was going to these other countries.

Heumann: Right. I think we were away six weeks. In Scotland we went to a youth program also. In Sweden we were just doing more visiting programs, as I recall. In England we were visiting programs.

Brown: So they were basically paying for you to go. What was their angle on it? Just to have more input from a disabled person?

Heumann: Yes, and they wanted that representation at the meetings.

Brown: So you were representing them?

Heumann: Right, at the camp programs.

Brown: Did they do all the organization in terms of where you would go and where you would stay? Who did all the logistics? You didn't, obviously.

Heumann: No. I'm sure that I was involved in helping with it, but two of the programs you went to a place, and then they took care of everything.

Brown: The camp.

Heumann: Right. I think that the affiliates helped, their affiliates help, and they probably did the ticket bookings. But why don't you ask the questions.

Brown: Okay. I wanted to know where exactly you went, how long you stayed, if you can remember. A little of that you've already touched on. Then what you did, if you can kind of go place to place, as much as you can remember.

Visit to Norway

Heumann: Yes, sure. Twenty-five years ago. The Norwegian trip was very interesting because it was really an international meeting. The Scottish program that we went to was mainly Scottish people and Jan and I. The only activity that I recall that we participated in which had people from around the world was the program in Norway. I remember in Norway we did some sightseeing. I remember we went to the Statue Gardens. That was very pretty. But the camp program itself, there was a camp, but there was a focus on learning from each other, opportunities to be together, to talk with each other, to learn from each other. Kalle and I became very good friends at that point. There was a woman named Mercedes from Spain, and a guy, Theo, who was blind, from Denmark, I believe. I don't remember who else was there. We spent a lot of time together. There were discussion groups and just general activities of boating and outdoor activities, you know, just camp.

Brown: Was it focused on disability?

Heumann: Yes, it focused on disability. About half to two-thirds had different disabilities. It was people from around the world. It wasn't that big a program. I probably want to say fifty people. We had discussion groups.

Brown: Do you remember what you discussed, the topics?

Heumann: The topics? Not specifically, but generally. I'm doing your interview in twenty-five years. "Do you remember where you went on the second?"

Brown: [chuckling]

Heumann: It really was learning about what was going on in people's countries and sharing information and general discussions about people's perceptions. Again, we weren't talking about movements per se because that language wasn't really used that much then. But they really did focus on the environment: what problems were, what governments were and weren't doing, what we were interested in achieving, what we saw as barriers to that, successes. It was good because it was a good atmosphere. It was very pretty. I don't remember the name of that. I want to say it started with a "T" or an "L." I'd like to see a map.

I remember one funny incident. We were having dinner, and I was eating this meat, and I thought it was beef, but it was a little soft for beef. I asked what it was, and it was whale. One of those international experiences where you're sorry you asked but you have to keep eating?

Then I remember they didn't like the Swedes.

Brown: Who didn't like them?

Heumann: The Norwegians. Because of the war. I thought they were joking. I was saying we were going on to Sweden after this, and they were, like, negative. But I figured these countries aren't very big at that point. How could people not like each other? They were definitely not fans of the Swedes. They considered them profiteers because they had made money off of the war. They hadn't gotten involved, but they had sold arms. They were supposedly neutral, but—. The Norwegians, of course, had been in the war and were affected by the war, so there was hostility. I don't want to exaggerate it, but I remember.

Need for civil rights and benefits

Heumann: But for me it was a good atmosphere. We were talking to people from different communities, all of whom were doing some work in their community on disability issues. Kalle, of course, because at that point—let's see. Did I go to Berkeley right after that? Yes, I did. I went right after that. But I didn't really know what CIL was. I mean, I had a quick vision of it. So it was very interesting to me that the program that Kalle had set up, was setting up, was very similar and basically the same as the CIL program.

Brown: Was that Threshold [an independent living center—the first in Finland]?

Heumann: Right. Other questions?

Brown: I was just wondering if there was anything else you wanted to say about that, that you can remember.

Heumann: About Norway?

Brown: Were you surprised by anything that you learned about the disabled people in other countries?

Heumann: No, because I had been in Germany and Sweden and Australia the year before. I don't recall being surprised. There was this general, common problem that everybody was facing. Again, it was a reinforcing for me of learning about what the Scandinavian countries and European countries were doing, but I wasn't any longer surprised, really, because I already had a broader understanding of what we were doing and what others were doing, so it was just continuing to add on to what I knew.

But it reinforced the same types of discrimination. At that point, I think Kalle was also involved in civil disobedience. The others weren't, really, as I recall. But we certainly had been because I was still involved with DIA at that point.

I remember being on a boat. It was a nice boat. I remember staying up for hours and hours, talking. You know, just long conversations. I think it continued to reinforce an understanding of the bigness of the world. The person who was there from Africa was from Botswana. She was a white nondisabled woman. She was from Botswana and had lived there, I think, her whole life, but she wasn't black. I'm trying to remember [pausing]. What I have thought a lot about—not in the last few years—when I was at CIL and what I liked about that place and I thought would be good was it was a year-round camp. The Norwegians used it to bring people together to spend a week or more and discuss issues. I always thought I'd love to be able to have a place like that in the United States, where we could bring disabled people together or disabled people and nondisabled people together, just in a loose but structured environment, to really have opportunities to talk to each other and learn from each other and share information together.

Those kinds of environments are very important for people, just to get a better understanding of who each other is and what makes you tick and what your goals and aspirations are, especially because it was a similar kind of group of people. But definitely I left there once again feeling—that was true for the whole trip—like at that point already the civil rights approach to what was going on in the United States was beneficial. It was at that point, really, in '72, '73 that I really did start saying that I thought that we need a combination of systems. Because I saw value in each, and that independently it didn't seem that we could get where we wanted to go.

Brown: With just?

Heumann: Just the U.S. type of model, or the European or Scandinavian.

Brown: Civil rights or just benefits.

Heumann: Right, that it needed a combination of both. Certainly, the whole empowerment aspect of what people were involved in was central. But you needed an ability to have something in place, particularly for individuals who had more significant disabilities—could be covering costs that were beyond what the typical person had to pay for things.

Visit to Sweden

Heumann: Then we went to Sweden. I wrote to the people that I met in Norway for a number of years, I think, including the woman that Kalle came with, whose name I can't remember, but the attendant that he had. She was very nice. I don't know if I saw her again when I went to visit Kalle years later. But it left a good impression on me.

Sweden, when I was there, I was visiting programs, and it was similar to what I had done the first year, but it was learning more about their housing systems and more about their benefit programs. I think we stayed in a hotel, did a little bit of sightseeing.

Fokus housing in Sweden

Brown: So you were going to housing programs? What sort of programs?

Heumann: Well, they had—I think I did mention it to you before. What's it called?

Brown: The Fokus houses?

Heumann: Fokus housing. Other types of supported living model programs that they had. I think I met with a social worker, and I met with some disabled people while I was there. I think I visited some of their organizations. They did have more disability involvement in some of their traditional organizations.

Brown: More than in the U.S.?

Heumann: Yes.

Brown: Or more than the other countries, like Norway?

Heumann: I have no idea about Norway. More than here. They got support from the state to run those organizations. I remember laughing all the time because we had so much difficulty getting money to do anything, and you never really saw the government easily giving out money to people to advocate for things. So Sweden just kept reinforcing things that we didn't have. I know that there has been a lot of criticism later on in the years about Fokus.

For its time, in comparison to what we had here, there was nothing because they had a certain number of units in a building. Everybody was not on one floor. They were on one area of the building, but they weren't segregated off. They had two apartments on each floor. Then there was a room downstairs where they had the personal assistants. They would call, and people would come up, and they would schedule when they needed their help, and they were involved in the hiring and scheduling.

But, of course, the problem with the program was that because you didn't have your own person, even though you had a lot more latitude than if you had nobody, it still didn't give you the latitude that you could have if it was a program where you could hire based on your interests, your needs, and when you needed somebody.

Brown: Was that a problem that you saw when you were there, or that was something that occurred to you later? I mean, did the residents themselves point that out as a problem?

Heumann: No. Remember, this was a regular apartment complex. They were just tenants in a building. No one saw it as anything different because the Swedes were very into percentages. They were closing down their institutions. They had—and still have, I think, I'm sure, rather—benefit programs that provide a much broader array of support than we do here. I don't remember the disabled people that I met there, but I think I met some people from the sports clubs that they had there.

Brown: You didn't meet Adolf Ratzka?

Heumann: Adolf wasn't there then. I don't think so. I didn't meet Adolf until the eighties. I don't think I met him then. I think he maybe was just going there, from L.A. [Los Angeles] or Berkeley, but I don't think so. I should ask him, but I think the first time I met Adolf was in St. Louis. I think so. Shall we call and ask? Too late.

Brown: Anything else that you can remember about that particular Sweden trip? I know you went there a lot, so they all might kind of run together.

Tech center's new program

Heumann: No. Again, I think it was visiting different kinds of programs, different associations, getting a better sense of what was going on there. I did realize at that point, too, that although they had many different programs, they had a very high unemployment rate. I think I visited one of their tech centers, which I was very impressed with because you could go to one place and look at all different kinds of medical equipment, and you could take things home and try it out. Nobody was there selling anything. Manufacturers didn't give for display; the government purchased.

What that meant was that you weren't getting any hard selling for anything. It was like they would have five different types of picker-uppers. They were doing work on bathrooms and kitchens and all types of other things. That very much struck me, also, that they were—from what I knew here—they were doing a lot more in trying to get things into the hands of people. We still don't have these tech centers at all.

I want to say they had eighty-some in Sweden, in your communities. You could drive and visit them. They had OTs [occupational therapists] on staff who could help you look at what you needed or thought you might need, and then the government would pretty much pay for it if you needed it. That was foreign.

I remember Jan and I going outside, down the street at the hotel we were at.

Experiences in Scotland

Heumann: Then we went to Scotland. In Scotland, gosh, I want to say that was more fifty-fifty disabled and nondisabled people.

Brown: In terms of who you were meeting with?

Heumann: There was a program.

Brown: Oh, this was the other camp.

Heumann: You know, I remember in Scotland we stayed at, like, a bed and breakfast. You had to put money to get heat. I remember being shocked by that. It was cold there, and it was the summer. I remember—oh, goodness—so cold for the summer. What I remember about that the most is that we were taking an improv class, and somebody had a seizure, and nobody knew how to take care of it, how to help the person while they were having the seizure. I was telling them verbally what to do and worried that I wasn't doing the right thing because, of course, I really didn't know what to do if somebody had epilepsy, when they were having a seizure. I think I had heard something, so I was saying, "Turn them over and put something in the person's mouth and move stuff away." It turned out later that it wasn't a real seizure. The teacher had just wanted to do it for the acting class.

Brown: Wow.

Heumann: I remember being very upset, although it was a great exercise because no one knew that it wasn't real.

Brown: It was a student, but the teacher had set it up with the student?

Heumann: Right.

Brown: Wow. Was it mostly disabled people or this was the group—

Heumann: This was a mixed group. I remember thinking, Oh, my God. I was so worried about something bad happening to this person. But it was really to demonstrate, I guess, being able to work together. So, from that perspective, it was a good exercise. Did a good job. But I remember thinking, Oh, my goodness. Because I was so worried that something wasn't right.

Brown: So you kind of took charge.

Heumann: Exactly. I did.

Brown: But weren't really sure you were doing the right thing?

Heumann: I mean, it's not that I just jumped in. The guy started having a seizure. Nobody did anything. So it was, like, somebody had to do something, but I couldn't do it myself, so I had to—

Brown: Direct.

Heumann: —direct people on what to do.

Would you cross my foot, please?

Brown: I'm just thinking that might just be a metaphor for many parts of your life.

Heumann: Right. But I do remember that.

— 219 —

Bad durable medical equipment

Heumann: Now, this was interesting because the quality of what people got in Sweden and Norway—Sweden in particular, because I didn't really visit systems in Norway, so I couldn't really speak to what they did or didn't get, from a DME [durable medical equipment] perspective—but in Norway they have very similar types of services to Sweden and Finland. The Scandinavians—their systems are different—I mean, Finland is different; they're each different. But there's more of a thread.

But I remember when I was in Scotland, somebody was sitting in a wheelchair, a decrepit wheelchair, like if I were to have thought of it, I would have thought of the Poles when I saw them at the wheelchair games in Germany, whether they really used those chairs in Poland or not. The manufacturers and everybody felt so badly for their equipment, they gave them new wheelchairs.

One day, this person was sitting in the wheelchair. It had cloth seating and cloth back. The chair just collapsed. I remember laughing and thinking, What a piece of garbage. You would hear people in Britain talk about, Yes, they got stuff, but what they got was really poor quality. It really wasn't meant to help you and get you around. I mean, I remember I had a wheelchair in the States around that time, a manual chair, and it had broken. The wheelchair company had told me that I had gone up and down too many curb cuts.

Brown: Curb cuts?

Heumann: I mean, up and down too many curbs. That the chair wasn't an outdoor chair. I'm like, get a life. It was a regular EJ [Everest & Jennings] chair, but their equipment was really bad.

I think it was in Scotland that someone donated time in a small airplane to take all the students up? I think that's where it was. I sat in the car the whole time because I was not—

[Tape 15, Side B]

Heumann: I was not at all interested in going up in this small plane, so I sat the entire time, reading a book in this car.

Brown: But the whole rest of the group went up in the plane?

Heumann: Everybody.

Brown: But you.

Heumann: It was one or two people at a time. It's a little plane.

Brown: Didn't want to go.

Heumann: No. Had no interest. I remember my friend Tony had said little planes are fun and safer and dah-dah-dah-dah. Not me.

— 220 —

Brown: Do you remember anything specific about the group in Scotland, or you did things differently from the group activities that you did in Norway? I mean, I'm assuming, because it was a mixed disabled-nondisabled group, that it would have had different dynamics and different topics.

Heumann: Yes. I don't remember how long I was there. I had been there less than six weeks? Scotland's a pretty country. I don't remember any of the people I met.

Horrible experience in England

Heumann: Now, England—that was an experience. What was the name of the town we stayed in? We stayed in a little town. First of all, the trip was organized by a woman I later found out hated Americans. Her sister had married an American soldier who had taken her back to the United States, and she hated the United States. Of course, no one realized that when she was setting up my itinerary.

We stayed in this little community, where they had a longterm rehab unit. The warden, which was what they called them, was on vacation. I had flipped that place up in the air by the time that warden got back. They had staff wearing white coats, they had restricted hours. I remember Jan and I talking—

Brown: This is where you were staying?

Heumann: Right. This is where they put us up—not in a hotel, not in London, but in this place outside of London, where they didn't allow you, in a wheelchair, to go to the movies by yourself. She never had anything planned in the evenings for us, so we'd have to go back to this place at night, and we didn't know anybody. We didn't have a car. Jan didn't drive. It was—

Brown: Rolled eyes [describing H.'s expression].

Heumann: But I visited numbers of programs. I did go into London, but no sightseeing. The whole time we were there, she had no sightseeing for us. I mean zip. We visited a place called Loughshire, an ergonomics program. A man named Terry and his wife, who I had met in Australia. They were very nice people. They went to visit the program so they could show us what they were doing. They were testing equipment to see not just about the stability of the equipment but also to be able to look at things like people have different types of disabilities. How could the various forms of technology—vacuum cleaners, whatever—be utilized by disabled people, and which types of disabled people could use which types of things more readily? Vacuum cleaners for a one-armed person or different types of—

Let me talk about Loughborough, and then talk about the train ride we took.

Brown: Did you say Loughborough? Or Loughshire? Are those two different things?

Heumann: Loughborough.

Brown: Okay, so talk about Loughborough.

— 221 —

Heumann: I think we had a barbecue. We sat outside. We were talking. We got into talking about the different—how did this go? They had all these clubs, like the disabled horseback riding club and the disabled this and the disabled that. I think while I was there I did actually visit one of these horse riding—I did. We've got them here, too. They look very nice. I don't remember if it was the person who came to pick me up or somebody came to pick somebody else up, but I went over to the driver of this vehicle and said, "Do you have any clubs for disabled people and sex?" I remember Terry and his wife laughing. I said, "You've got horseback riding clubs, disabled swimming, dah-dah-dah-dah. So I just was wondering if you have a club for disabled people and sex." Terry and his wife were, like, funny people, so they just laughed because it was me. But the guy who was picking this person up just was dumbfounded.

Ride in guard's van

Heumann: We went on a train one day to go visit some programs. We had to sit in a place called the guard's van. Do you know what the guard's van is?

Brown: [no audible response]

Heumann: We didn't, either. But the guard's van is where they ship the cattle.

Brown: [laughing]

Heumann: Newspapers. It had no insulation for sound or heat. So there are Jan and I, in a cage, literally. Freezing because it was cold, even though it was the summer. We didn't have any cattle with us, thank goodness.

Brown: It would have been warmer.

Heumann: It at least would have been more interesting. Because we couldn't get on the regular part of the train. Then this guy Chris came to pick us up at the end. I had been talking with the people living there, "You need to take more control over your lives. Do you really like living in a place where these people are wearing these stupid white coats? This is your home." Oh, and they had this bus. I mean, it wasn't a van. It was a bus, a bus. It was kind of on the Trailways version. Had a lift on it, and they would take people out on outings. But it was a bus. You have to understand proportionally this was like a town. This bus was bigger than anything they had in the town, and it had—whatever the name of the—Jan died. Jan was murdered in Berkeley. But anyway, Jan Balter. When Chris came to meet us, he had his white coat on. I said, "I am not leaving with you in a white coat. You either go back there and take that stupid white coat off and come back and get me. I am not going with you."

Brown: Was this the driver? Chris was the driver of the bus that came to pick you up?

Heumann: Yes. I'm not sure if he was driving or just came to pick us up. He worked for the facility. Then we went to some program.

Brown: Well, did he take it off?

Heumann: Yes, he went back and took it off. I wasn't joking. I'm like, this whole thing is mortifying enough. I mean the stupid guard's van. I can't go to the movies because they won't let a disabled person go by themselves. At this point, we just didn't understand why—because every day we'd ask, "So when are we going to London?" I think in Sweden we had gone to see a museum. We had done some sightseeing in all these other places, but literally the only sightseeing we were doing outside of London was driving from one facility to the other.

I did meet disabled people there, definitely. In one of the programs we visited, I met somebody from Rochester, New York, who had a boyfriend there, not a disabled person. They wanted to come over one night because I was saying we get home at six, seven o'clock at night, and there is nothing to do there. We'd talk to the people there and watch television, but we're near London! So she and her boyfriend came over one night. We were in the cafeteria, but at ten o'clock they wouldn't let us stay there. Everybody who didn't live there had to leave at ten o'clock at night.

I remember going outside. We were crouching—I was in my wheelchair—but they were crouching in between the cars because we were outside talking. The warden was back at this point, and sticks her head out—I think it was a woman—of her house, telling us that we're making too much noise. Which we weren't, of course.

Studies programs and talks with officials

Heumann: So London. I did learn many different things. I learned more about their systems, more about their benefit programs, lots of different organizations that I visited—government, nonprofit—was impressed with what I had seen in Sweden in comparison to what I was seeing there, although they had benefits beyond what we had here. There you could see the differences in countries. The Swedes had better than—

Brown: Everybody.

Heumann: Than everybody.

Brown: You said you met with government people in London? Did you meet with government people anywhere else?

Heumann: Yes.

Brown: What kinds of people were you meeting?

Heumann: I met with government people in Sweden—social workers and—

Brown: They were explaining to you the benefit systems in their countries?

Heumann: Exactly. I always wanted to learn more about programs, so I really made a point of doing that. I wish I knew where my books were. I took notes at all these places. I don't know where they are. I wonder if my mother has them.

Brown: Berkeley?

Heumann: You mean, my mother gave them to Berkeley?

Brown: No, I was thinking maybe you would have had them in Berkeley.

Heumann: No. Too bad, because I really did take lots of notes. Anyway, so that, overall, was a very good trip, but England was unimpressive. I could never understand why—and then the one day that they had—the last day we were there, they were supposed to take us sightseeing, and the bus broke.

Brown: Were they going to take a whole bunch of people?

Heumann: No, that's all they had. I don't know if they were taking a bunch of people. I don't remember. All I know is the bus broke, and we didn't go, so I saw nothing of London, nothing outside of visiting meetings. They weren't all government; there were nonprofits also. It was combinations of things.

So that was the trip overall. A good experience for me.

[tape interruption]

Different political structures

Heumann: I mean, the trip allowed me to continue to learn—I think as I've said a number of times—about different political structures. Even such things as different parties in the United States, where there are two parties. You learn about in school different parties, but there's just something different about actually being in other countries and hearing people talk differently about different parties. I think the Greens were—I'm trying to remember. Were the Greens just starting in the seventies, or was that the eighties? I was meeting younger European people, who were free thinkers.

Also the ability to see the differences of benefit programs, being able to put ours in comparison to other programs and to do the comparisons and contrasting. Just to be able to meet people from other countries where I've always been interested in, seeing people with diverse backgrounds.

Brown: Were you always interested in doing international work? Or was this sort of a generic interest in people from other countries?

Heumann: I was young. I was twenty-five. I hadn't really thought about doing work in other countries, but that in part was disability-related, too. I mean, I wouldn't have thought about it because it would have seemed pretty impossible to do. Different weather, different sun, just learning about differences, and seeing how the needs or the desires of disabled people in my age range were very similar—for some. They had kind of the broad range—those who were more political and those who were not. Even on that trip, I really got the extremes. You know, Kalle and myself on one end and the people living in this residential program, which had been a nursing home, which now is supposedly no longer a nursing home. I mean, people had their own rooms, but it was still very much a nursing home because they didn't have control. Although people tried to say they did, they didn't.

Brown: Okay. Did you know much about disabled people in other countries? I mean, obviously, you went to Germany and Australia and was it Sweden before? But was a lot of what you were hearing from Norway and the people from other countries new information to you?

Heumann: Yes. I think at the President's Committee sometimes I would meet some people from other countries. Certainly, my family was all from other countries, so on one level everyone my parents' age, on both sides of the family, hadn't grown up in this country, so you learned about other systems because people talked about their past, although, of course, what they talked about was a lot about prior to the war and what was going on.

It was mainly new. You'd read things in the paper about international activities, but disability was certainly never discussed. That was very new, meeting disabled people from other countries.

Brown: Had you traveled a lot in the U.S. before you were on these trips?

Heumann: No, we never traveled a lot. I mean, in the summers we would go to camp. I went to camp from when I was nine until I was about—oh, probably eighteen.

Brown: Did you drive? How did you get there, driving or by train?

Heumann: Drive.

Fear of flying

Brown: But you didn't take a plane.

Heumann: I didn't take a plane till I was in college.

Brown: Where was that to?

Heumann: Champaign-Urbana. That was the first plane ride I ever took, to visit a woman named Karen Rose at the University of Illinois. Or was it SIU, Southern Illinois University? Anyway, that was the first time I ever flew.

Brown: Do you want to talk about that, that trip, that flight? What was it like?

Heumann: I was a little scared, but I was excited, too, because it was the first time I had ever flown. I think I had to change planes. They helped me. They were very nice.

The second flight I took was eventful. I think I went down, actually, to visit the same person, who was now in Alabama. Her husband was in the military. Coming back, the flight was terrible. It was very turbulent. I remember being totally freaked out. I was reading. At one point, I had the book upside down, and people were throwing up. It was amazing. There was a woman, diagonal to me, who was sitting with her feet curled up under her and reading a book, as if she was totally oblivious to this storm and turbulence and, literally, people upchucking. She was a stewardess. Now it's called flight attendant; in those days, stewardess. No big deal to her. I remember that. I was trying to talk to her to kind of figure out [whispering] why is she so calm and everybody is so freaked out? [Resuming normal volume] I did ask her, "What do you do?" "I'm a flight attendant." "Oh, okay."

So these are the first two times that I flew. Of course, then when I went to California, then I started flying.

Brown: A lot.

Heumann: But my parents didn't fly. I don't know when they first flew. They didn't fly to the United States. They took boats. My father probably flew in the military, but he was also on boats.

Brown: Now, I know from traveling with you that you are not always the most calm person about flying. When did that happen, your fear of flying?

Heumann: My fear of flying was more in the beginning. I'm a much better flyer than I was then. Then I was, like, really—

Brown: That's what I would like to hear about. Would you talk about what it was like for you when you first started flying and you were more afraid?

Heumann: You know what? I don't recall in the very beginning being that afraid. I don't know exactly what happened. It could have been that flight. The time that I was arrested on the plane—what was so comical about it was I was reading this book called *Fear of Flying*. In the beginning of *Fear of Flying*, it does talk about her fear of flying. I was in that section of the book when this incident happened. I remember thinking, This is too bizarre.

Southern Comfort in a flask

Heumann: My father had gotten me a flask, and I would drink Southern Comfort before I would get on the plane, on the plane. Years later, I would take Valium; then I took Xanax. I stopped taking anything when I started flying with Gaby Brinkman [Hunter]. I thought she's kind of like my goddaughter and it wasn't going to be a good example for me passing out. I drank, but I didn't get drunk at all. That was just to calm me down. But I would take the Valium or the Xanax and I'd fall asleep. She was also afraid of flying. I thought, I can't be falling asleep and I can't let her take what I'm taking. She was supposed to be able to help me if I needed help.

Brown: So what would happen?

Heumann: When I flew?

Brown: Yes.

Heumann: Oh, I would grab onto your arm. It would really depend. I could almost cry. Michael Winter—we were once in Hawaii. We were flying, and he said something, teased me, "The plane is going to crash," and I was almost ready to cry. "Michael, stop it! Stop it!" I don't like to think about it because I've been trying to get myself calm around flying, so I actually don't talk about it a lot.

Brown: Well, this is for history, though, so we can briefly address it and then you can go back to a person who's not afraid to fly anymore.

Heumann: Right. That's because I kind of mask it over.

Brown: Blank it out.

Heumann: You know, at some point you make a decision that you're going to fly. If I didn't fly, I didn't get to do what I wanted to do. I've flown so much that after a while, it's just a way of viewing it. I've never been like a friend of mine, Carol Jenkinson, who actually doesn't fly. She's totally freaked out about flying.

Giving up control

Brown: Were you afraid that it would crash?

Heumann: Oh, sure. It's being out of control for me because then you have to depend on other people if anything happened, so it wasn't just that the plane could crash, it was that I had to depend on somebody else. Flight attendants would always make it very clear to me that in the event of an emergency, I would be the last one off the plane if I was lucky.

Brown: If you were lucky, they'd get you out.

Heumann: One flight, this very nice woman comes over, kneels down next to me, and says, "I just want to go through the procedures with you. If there's an emergency, you'll be the last one off the plane, and we'll do our best to get to you." I think it was even in first class this time. I remember a little bit later I said to her, "You know, I have a real fear of flying, and I just want to tell you that coming over and telling me that you may get to me and you may not, is not exactly a great thing to tell somebody who is afraid of flying. Actually, I bring my own person with me, just so I don't have to depend on any of you."

But the truth of the matter is it's like giving up control. I'm not in my own chair; I can't do anything for myself. Now, theoretically, everyone is in the same position. But unless they get significantly injured in the crash, they can try to get up and try to help people, which I would be less than useful. So I think that's all part of it. You get older. I have different reactions to it.

Brown: I remember being on a plane with you. They were showing a video about what to do in the event of—

Heumann: An evacuation?

Brown: Then the little slide would inflate, and you should jump straight out with your—

Heumann: Legs.

Brown: Straight out in front of you. I just remember we both cackled hysterically because it was the funniest thing.

Heumann: I'm going to get all broken. What in the world is going to happen to me? I'm going to be, like, "Please, you've got to hold my legs out in front of me, and you've got to do it carefully." American Airlines at one point wanted people to sit on blankets. I think it was for a couple of reasons. Some people said it was because if you couldn't go the bathroom and you had an accident. So people were very against using the blankets, so, of course, I never used the blanket. But I did think that there was a value to the blanket because in the event of an emergency and the plane wasn't completely destroyed, two people could pull you on it, and your legs would be in front of you. But politically incorrect people say that because people hated it. I was the last one that was going to say, "It's okay, I'll use the blanket." I hated American Airlines anyway, so I definitely didn't say that.

Brown: When I fly with you, Jude, I'll get you off the plane.

Heumann: Now I pull bra straps. I don't know what it is. I like to put my hand behind somebody. Don't ask me. I have no idea.

Brown: And grab them and squeeze very, very, very hard.

Heumann: No, I don't squeeze hard anymore. I just grab the bra strap.

Brown: Well, you were still squeezing a year ago [chuckling]. Very hard when we hit turbulence. Very hard.

Heumann: With turbulence, yes, probably.

Brown: Since not all of your attendants need to wear bras and therefore don't—

Heumann: Grab his shirt.

Brown: Just grab whatever they're wearing.

Heumann: That's right.

Brown: And clench it very, very hard.

Heumann: That's exactly right.

— 228 —

Brown: Well, I did want to know a little bit more. I also heard a rumor about you traveling with a blanket over your head. Was that a false rumor? You never did that when you were afraid?

Heumann: No, I'm afraid of the dark.

[cross-talk]

International travel issues

Brown: So more on the subject on traveling and flying with a disability. Did you find that it was complicated to travel? Particularly, I'm wondering internationally. Did you have problems with people not wanting to help you or not knowing what to do with you? Not getting into the incident where they arrested you because we'll talk about that later.

Heumann: You know, the international flights in the beginning, I don't remember a lot of difficulty with them. I wasn't locked into U.S. carriers, and I think I might have even taken European flights. Now, the first trip I took to Germany, as I said, I flew with this big group of guys, so there was no problem, any of those trips.

Actually, I remember going to Australia. It was great. We had this really nice guy, who was the steward. He actually picked me up and took me into the bathroom. He was so nice. The trip was great, even though it was a crazy trip because we had to stop in San Francisco and Hawaii because the weather was bad. It was terrible. It took us so long to get there. But this guy was great.

Coming back, which is boring, I don't recall, which doesn't mean there wasn't a problem. I think I traveled with my motorized chairs. Yes, I definitely think I did.

[Tape 16, Side A]

Brown: So it wasn't a problem getting the airlines to bring your chairs?

Heumann: I'm thinking of the international travel. I don't remember. In the States, certainly, it was. But internationally, I don't remember in the beginning. Certainly later on, there were times when it was difficult to get them to bring the chairs up. In the very beginning, I may have just let them put me in a chair and take me down. That's probably what I did.

Brown: To baggage claim?

Heumann: To baggage claim. I remember in the beginning I would go a lot to baggage claim.

Brown: So in the beginning you did let them.

Heumann: In the beginning I would let them take me down to [crinkling sound].

Brown: That's the chocolate chip cookie wrapper being wrinkled. You'd let them take you down to baggage claim and claim your wheelchair there?

— 229 —

Heumann: I had less difficulty in those days getting lifted. The older I've gotten, the more cautious I've been about being lifted.

Brown: Because if you were lifted wrong, it wouldn't have affected you as badly then?

Heumann: I was just younger. I was stronger. I could help more. I weighed about ninety-five pounds then. I'm about ten, fifteen pounds more. Oh, to be back there, but no. The thing is, when you're first doing something, if there weren't terrible incidents, they don't really make much of an impression. It's the accumulation of things.

Brown: So you didn't notice at the time that it was significantly better or worse to be traveling internationally, but it doesn't sound as though you had done much domestic travel at that time.

Heumann: Right.

U.S. versus international travel

Brown: At this point now, though, do you think there is a big difference between traveling internationally and domestically?

Heumann: I think it also depends on the airline. Lufthansa I had trouble with. Since I've been working for the government, I can only take U.S. carriers. Everything is hit and miss. Sometimes it's a disaster; sometimes it's okay. I mean, in Germany they have this, or had—I don't know if they do anymore—I haven't been through Frankfurt in a number of years. When I was through Frankfurt, they had this separate health clinic, and they made you go to this health clinic. The first time I was there, I had no idea what was going on. If you don't know what's happening and you're in a foreign country altogether, they'd pick you up off the plane.

One of the differences in many of the European carriers—but it's not just European carriers—because once you get to the other country, you use the in-country people. They're more likely to use ambulance-kinds of people. On the other hand, the people they use are much more likely, really, to be able to lift you. So you may not like certain aspects, but part of the problem here with these jobs is they're low-paying jobs, and so you tend to get people who are the more recent immigrants in the country. Like, in San Francisco, I don't know how it is, but they've got a lot of Filipinos who do lifting. Generally, these guys are very short.

Brown: Little.

Heumann: And little. They've got bad aisle chairs in many cases; they don't even have the new ones. They're not trained anywhere like, typically, the Europeans have been. Now, Japan—I don't get the sense of feeling as vulnerable when I am traveling internationally, at least the airlines I've used, even though they may have bad attitudes and everything else. They're typically stronger.

— 230 —

Goods and bads of trips

Brown: I think you already addressed this, but how did you feel about the trip to Europe before you went?

Heumann: Before I went? I was really glad I was going. It was exciting. I was going to be going to four countries, and I was just going with a friend. I thought, Oh, this is great. I was very interested in what I was going to learn.

Brown: Did you learn any phrases? "Where's the bathroom?"

Heumann: Oh. I didn't need them in Scotland and England, and in Sweden everybody spoke English, and in Norway everybody spoke English.

Brown: So you were fine. What were some of the best things? I know you already said some of the things, but just off the top of your head.

Heumann: Making friends with Kalle. I think that was the most important of that trip. He's a good friend. He's kind of a soul mate, even though I haven't spoken to him in about three or four months.

Brown: He had a strong influence on your thinking, did he? And you on he?

Heumann: I don't know. I think to the extent that we had similar ideas and we reaffirmed each other, he definitely did for me. It was a short time that I was with him. Over the years, he certainly has. I also admire a lot of his skills. He's a man, so he's got that part of him, too, even though he's got all these other things, and be a little macho guy. But I like him a lot, respect him a lot. Learned a lot from him.

Brown: What would you say about the worst things you remember about the trip?

Heumann: Oh, just this part in England. I mean, that was just anti-Americanism when you didn't even know it. I kept thinking, "Look, honey, I'm sorry that your sister went off to the United States, marrying a guy from the States, but if you were like this then, she probably was smart."

Brown: To get away from you? [laughing]

Heumann: Of course, in England I felt very oppressed based on disability. Rehab International, as primarily a nondisabled organization, certainly then, it kind of, in the back of my mind, just reinforced that if Rehab International would have sent a nondisabled person over there, I really didn't get the feeling that they would have been so disrespectful, which is what I really kept thinking. This is so disrespectful. I thought, Well, if she didn't want to host the trip, she didn't have to. Hardly ever saw her.

Brown: Was she a Rehab International employee?

Heumann: No, no, no. The chapters were volunteers.

Brown: Oh, so she was just a volunteer.

Heumann: Yes, yes.

Brown: Anything else you want to say about your trip, the exciting summer of travels?

Heumann: No. Nice scenery.

Brown: Nice scenery! Fun to be in a train car with the cows.

Heumann: The boat. I think I went on a boat ride in Sweden. The fjords. It was all pretty. Yes.

Okay, next.

Applications to graduate schools

Brown: All right, we're moving into graduate school. I'd like to start by asking you just a bunch of general questions about your decision to go to Berkeley. How did you decide?

Heumann: To go to Berkeley? Well, did I tell you that I had been accepted to Columbia?

Brown: I knew that, but you could talk some more about that.

Heumann: I think we talked already about how I had to have a master's degree in five years.

Brown: For your teaching.

Heumann: For my teaching. I had taken this one course at Columbia in community organizing and had really liked it and thought, Oh, I'll apply to Columbia and get a degree in social work with an emphasis on community organizing. So I had applied, and I got in. That, of course, was interesting to me because undergraduate school was so complicated for me—getting into undergraduate school—my grades weren't bad; I had, like, an 88, 89 average. But I got rejected from a number of schools. So I didn't know what was going to happen in graduate school. But in graduate school—I got accepted to really good schools.

Brown: Where else did you apply besides Columbia and Berkeley?

Heumann: No place.

Brown: But you got into them.

Tries for Oberlin Law School

Heumann: I got in. Nothing. No, I actually applied to law school.

Brown: I was going to ask you about that. That was in New York, right?

Heumann: No, that was here. That was in D.C. I applied to Oberlin Law School. That was in the seventies. I knew Ralf Hotchkiss. He went with me to the interview. We never talked about this?

Brown: No, we did not talk about this. I found a reference letter from someone, saying you would be a good candidate for law school. But I thought it was dated earlier.

Heumann: Well, it was somewhere between '71 and '73, because I needed to go back to school, so I was thinking about law school. I actually took the LSATs [Law School Aptitude Test]. Those tests were the worst for me.

Brown: Were you thinking of law school? Was that partly your experience with the lawsuit?

Heumann: Probably. The lawsuit. Plus all the work I was doing in DIA. I thought, Well, being a lawyer; that would be good.

Brown: Why did you decide not to?

Heumann: I didn't get accepted to Oberlin. I was interested in Oberlin because it was supposed to be this kind of alternative program, where you were involved in clinics and other things very early on and you weren't just in school the whole time. I remember coming in for this interview with Ralf and myself, and Ralf and I leaving this interview, thinking, forget this. They were totally freaked out at my wheelchair.

We had to live with a family for a period of time. I don't remember how long it was.

Brown: Where was this?

Heumann: Oberlin.

Brown: In Ohio?

Heumann: No, they had an Oberlin law program. It's closed now. I think it only lasted six years. But anyway, I don't know why I didn't get accepted. I don't remember. But Ralf and I knew when we left that interview that I wasn't going to be accepted.

Contact from Ed Roberts

Heumann: So I had been accepted into Columbia. I got a call from Ed Roberts, who I didn't know, who told me that he was involved with this organization called the Center for Independent Living, and they were looking to bring a few disabled activists from different parts of the country out to Berkeley to go to school and to get involved with the center. He had gotten my name from a lot of different people around the country. Would I be interested in coming out to school there?

I remember continuing to ask him questions because I couldn't imagine how I could not be living in New York because I had such a system here. He explained about himself and what he did physically, how he used personal assistants and how they had an IHSS [In-Home Supportive Services] program and how I could probably get Social Security. I figured how was I going to get any money? I don't know. I guess Rehab was going to pay for me to go to school here, in New York. I wasn't worrying about money.

Brown: Money for school.

Heumann: Yes, and just living. I spoke to him.

Brown: Had you ever heard of Ed before he called you?

Heumann: No, he was an unknown person. I never heard of CIL.

Brown: I thought you—

Heumann: No, no. I had heard of CIL. I had just heard of CIL at the last demonstration, with Dick Santos and Larry Biscamp.

Brown: But you didn't know much about it.

Heumann: It was an unknown organization.

Brown: It didn't sound to you like something, oh, I'm going to drop everything and move out there.

Heumann: When I first met Larry and Dick? No, no. But they had told me a little bit about it, so when I spoke to Ed, I guess I had a little, little, little bit of information about it. So I applied to City and Regional Planning at Berkeley. That didn't require me to take the Graduate Record [Examination], GREs. Oh, that was another thing. I had sworn to myself that I was never in a million years taking one of those tests again.

Brown: After the LSAT?

Heumann: First it was the SAT [Scholastic Aptitude Test] disaster and the LSAT. I just do not test well, and I thought to myself, if I'm going to go to school, which I would like to do, I will not deal with these tests anymore. Too old. Been there, done that. Doesn't demonstrate what I can do. They didn't even ask me to take it. So it wasn't like I had to say I didn't want to take it. Columbia didn't require it, which is why I didn't take it for Columbia.

Acceptance at UC Berkeley

Heumann: I got accepted to City and Regional Planning, and a couple of weeks later—what had happened was that there were two professors—Fred Collignon and Henrik Blum—Fred Collignon from City and Regional Planning at Berkeley, and Henrik Blum from the School of Public Health. They, I guess, decided that they wanted to try to get some disabled students onto the campus. I mean, they had some, but in these programs. So they were involved with Ed—or Ed and they were working together—on trying to find some students.

What ultimately happened was after I had been accepted, a couple of weeks later, I got a call and said, "What would I think about the School of Public Health because they had accepted too many disabled students into City and Regional Planning?" Quite frankly, it was a blessing because I would not have lasted in City and Regional Planning but thirty seconds.

Brown: Because?

Heumann: It wasn't my thing. I mean, I'm sure there are courses there I would have liked, but some of the courses they had to take I was not interested in. So I kind of joked about it and said, "Yeah, okay." I didn't know what City and Regional Planning was. I didn't know what Public Health was, so it didn't really matter to me. If I was going to go out there, whatever. But Public Health was really a much better fit for me.

Brown: Did you find out more about it when they asked you that? Were you conscious that it was a better fit for you? Did it make more sense? Or was it you had these two options?

Heumann: Well, they told me to go [to] this one first. There were two places you could go. It was one of these things. Again, I mean, on a certain level there's something funny about this. When I went to Rehab, wanting to be a teacher, and not saying that and knowing that they were paying for women to become speech therapists and social workers, and saying I wanted to be a speech therapist and then say I should be a social worker, so here it was again, two choices, and I made the wrong choice. Here it was City and Regional Planning, and Public Health. Picked City and Regional—well, I didn't pick it. They asked me, "Do you want to apply for that?"

Funny. Limited options and still get it wrong most of the time! It's like should I go left? I go right. Should I go right? I go left. But I was terrified being in Berkeley. I think Zona [Roberts], no, Carol Fewell met me at the airport, I believe. I did not fly out there by myself. I got my friend Nancy D'Angelo, who later died—the two people that came out from New York, who I was friends with—both died. Both got heavily involved in drugs.

Brown: Nancy moved out to Berkeley.

Heumann: With me. We flew out together. We rented an apartment together. I was not going alone. She had a disability, so it was not that we were going to help each other out physically. But it was just that we could be moral supports to each other.

Brown: I'd like to come back to that after I ask some more before you went to Berkeley questions. Do you remember when the decision that you were actually going to go to Berkeley, when that was? Did you start school in the fall of '73?

Heumann: Yes.

Brown: But that summer you were traveling, did you know you were going to go to Berkeley before you went to Europe?

Heumann: Yes.

Brown: So you didn't visit the campus. You didn't visit at all before you decided? It was just, like, "Oh, I'll go."? Did you try and do any research to find out what it was like, or you just figured it's just for a couple of years; I can handle it?

Heumann: I didn't do any research. I didn't know who to research with. There were no computers you could pick up and say, "Show me Berkeley." I mean, I had heard of Berkeley, of course. It was a very good school, and it was a hotbed of political activism, at least in the sixties.

Brown: So you knew about that.

Heumann: Oh, sure. I knew about Berkeley. I just didn't know anything about CIL.

Brown: Or the city of Berkeley. I mean, the community.

Heumann: Well, you know, it's a small place, so you kind of assumed it was one and the same. No, I didn't do a whole lot of anything. I just did go. You know, you're right. It was like I was going to be there two years; I needed a degree; if I could get a degree at a good school, that would be great.

Indecisive about continuation of teaching

Brown: So that was your plan. You were going to go to graduate school, get your degree—

Heumann: And leave.

Brown: —and then go back to New York and teach?

Heumann: Well, I didn't know for sure if I was going to go back to New York and teach, but that certainly was a possibility. Honestly, I was burning out on teaching. The fact that I didn't go to get a teaching credential, to me, probably meant that I wasn't going back. But I hadn't closed the door on it.

Brown: Did you assume you'd be moving back to New York?

Heumann: Yes.

Brown: I was going to ask how did you hope to use your degree in public health, but it sounds as though you were just getting the degree.

[cross-talk]

Heumann: I was getting a degree—no, I was getting a degree in public health.

— 236 —

Brown: But, I mean, it's not you were getting a degree in public health so that you could then become a public health educator.

Heumann: No.

Brown: You were getting a degree, and it happened to be in public health.

Heumann: I needed a master's. They didn't care what your master's was in. The master's in community organizing made sense to me and actually even felt that if I stayed in teaching would be beneficial because it was the sociology of poverty and things of that nature, so I thought that could be helpful. But, no, really, it's kind of funny to think that I left and went completely to another part of the country. I didn't know anybody, but I did believe what Ed had said about the programs there. I did also feel like, well, you know, if it doesn't work out, you go back.

Brown: Right.

Heumann: Going with Nancy was important because I really would not have gone by myself. That was like having somebody there who I knew, came from similar communities, and so it kind of felt like there wasn't much to lose.

Brown: It sounds like there were two things that would make me ask this next question, and they're opposed to each other. The question is was it hard for you to leave the East Coast? You were very close with your family, but you also sort of thought you were probably going back.

Heumann: Exactly.

Brown: You'd only be gone for a little while. How was it, thinking about that?

Heumann: Again, it wasn't that I saw myself living there.

Brown: But you were to be gone for a few years.

Heumann: Right, but I knew I'd see my parents. I mean, I came home at Christmas. I didn't see them anywhere near as often as I did, but at this point I was twenty-five. I had a cousin who had gone to graduate school in Michigan. Actually, he was in Michigan when I was in California. My brother Joseph, I guess, was in Iowa. He had gone to undergraduate school. So when he had left to go to school, okay, I can do the same thing.

Contact with Center for Independent Living

Heumann: My parents visited. I think they visited. They did later on. I don't even know if they went there when I was first there, actually. I can't find out.

Brown: So you went to Berkeley for the school and for the community?

— 237 —

[cross-talk]

Heumann: No. It was clear that when I went out there, I was going out there to get involved in CIL and to go to graduate school. I was interested in seeing what was going on at CIL because of the work that I was doing in DIA, so it wasn't really just to go out to graduate school. It was going to graduate school, but I got elected to the board almost right away and got very active in the organization. I was kind of a second round of people. You know, I wasn't part of the founders, but I was pretty early on. It was September, October that I got onto the board.

Brown: When did you arrive at Berkeley, right before classes?

Heumann: Yes, pretty soon before.

Brown: August, September of '73?

Heumann: It wouldn't have been August. The schools usually started later there, I think. Whenever it was—

Brown: But it was only a month or two before you were on the board.

Heumann: Oh, yes. I actually lived in an apartment building on Haste Street, where CIL had an office.

Brown: Right next door, or really close?

Heumann: I don't remember if it was on the other side of the floor. The building that I was in had a courtyard in the middle. The building was built around the courtyard. There was a terrace around it. I don't remember if I was on the same floor or they were a floor below or something, but I could see them from my apartment.

First impressions of city of Berkeley and campus

Brown: What were your first impressions of campus? I'd also like to know your first impressions of the city of Berkeley. Pick and choose how you want to answer that.

Heumann: Hmm.

Brown: So Nancy came with you on the plane.

Heumann: She wasn't going to school, though.

Brown: Right, so she came with you on the plane. Did you fly into San Francisco?

Heumann: Yes. I'm not a wow kind of person. It's not like, "Wow! Wow!" It just kind of was. It was small.

— 238 —

Brown: The campus or the city?

Heumann: The city. Even though the campus was much bigger than the campus I had gone to, the city was small. For me, what I could do was I could get around a lot by myself. That I liked. There was an ability to go from place to place by myself, which I really couldn't do in New York because of the size. I could get about on campus pretty easily.

I went to the [Physically] Disabled Students' Program a lot because the bathroom was not accessible in the School of Public Health, so whenever I needed to go to the bathroom, I had to come back either to my apartment or to the Disabled Students' Program.

Brown: Were they on opposite ends of the campus?

Heumann: Actually—

Brown: Am I not sure where PDSP was then?

Heumann: It's Bancroft, and what's the street next to Bancroft?

Brown: I'm blanking. Towards where you used to live, on Regent?

Heumann: No. Wait [fire engine sirens] PDSP. Okay, here's Telegraph, here's Bancroft, right by the university—

Brown: And here's the campus.

Heumann: Yes, here's Bancroft, here's the campus. Okay, the street next—

Brown: Oh, PDSP wasn't on campus?

Heumann: Oh, no.

Brown: It is now.

Heumann: Do you remember where Top Dog is?

Brown: Yes.

Heumann: It was right behind that.

Brown: That's why everybody talked about Top Dog! It was, like, what was Top Dog doing on campus?

Heumann: It wasn't.

Brown: A blast of light for a poor young person who wasn't in Berkeley then.

Heumann: Right.

Brown: Okay, PDSP was not on campus.

Heumann: No.

Brown: But your apartment was even further away.

Heumann: My apartment was further from campus by a couple—well, Haste—

Brown: Two blocks, then.

Heumann: Not very far.

Brown: But still.

Heumann: Nothing was far in Berkeley compared to New York. That was the other thing. It was a town. I didn't like California, actually.

Brown: Why not? What didn't you like about it?

Heumann: I didn't think it was a very friendly place. I thought it was very phony. You got this impression that everybody really was friendly, but it was very superficial. I didn't actually like being there for about seven years. I didn't like the weather.

Brown: Why didn't you like the weather?

Heumann: Because it didn't have seasons, and it wasn't really warm a lot of the time, and it wasn't really cold. I remember for years complaining about how they didn't know how to insulate their buildings because they thought they lived in a warm area, but it was really cold because it was so damp.

I mean, I liked it. It certainly would be wrong to say that I didn't like a lot of things that were going on there. I liked DSP, I liked CIL, I liked the work that I was doing, I liked graduate school, I liked being friends with Ed. I had some boyfriends. Nothing of a serious mode.

I actually was traveling, though. I went back to Washington while I was in school. Not for my internship. I think I went back for the President's Committee. I was still very connected to New York.

[Tape 16, Side B]

Heumann: But I remember the first six months I was there, I gained ten pounds. I went from ninety-five pounds to 105 pounds, which I have never kept off again. I lost it once but gained it back after a few years. I thought I was eating very healthily. I mean, I was eating less meat, but I was eating more, I guess, and I was also eating things like avocado and trail mix and stuff like that. I remember going home in December, my brother weighing me, and being 105 pounds and being completely flipped out.

But it was easier to get together with people, which is what I liked, because it was hard for us to get together in New York. I didn't drive, so people had to come to me or I'd have to get somebody to drive me, which was always more difficult. But here people had vans and all of that stuff was great, and being able to hire attendants was great. Well, I had lived in my own apartment before, but before I had always had somebody in the apartment who helped me out. Here, Nancy and I had lived by ourselves. Actually, Nancy had more physical needs than I did. It was interesting that we went to live together. We were of zero help to each other once we were in bed.

Scared of Berkeley coursework

Heumann: I was scared in school a lot. When I had to go meet my professor, I was so in awe of him and felt so inferior.

Brown: Who was this?

Heumann: Henrik Blum. I remember one day I went to Ed's and I was crying because I had to go see him. It was, like, oh, my God.

Brown: Why were you so afraid of him?

Heumann: Because Berkeley—you know, everybody had to be so smart, and I wasn't as smart as all these other people, and so why did I get in here? Did they just take me because they had a special recruitment program where they wanted to bring some disabled people in? How was I going to measure up to everybody? There were some classes that I was just great in.

Likes studies at Berkeley

Brown: Could you tell me some more about what classes you took, what the courses actually were that you were studying, if you can remember? Just anything you can remember.

Heumann: Well, basic statistics was not one of my most favorite classes, and I got tutored a lot. I passed the sucker. I guess I got a B in it. Epidemiology, which I loved, primary health care—

Brown: What did you love about epidemiology?

Heumann: I liked the professor, the subject. I'm that type of a thinker: what caused the problem? Then having to investigate it and figure it out. I liked doing that. I do that all the time. What I liked about that program was public health's view was not narrow. Dr. Blum's view of health was universal, and systems impacted on each other. He didn't look at one system. For me, in trying to work on improving the quality of life for disabled people, I couldn't be one-dimensional. But so many people are one-dimensional. I mean, if anything, you'd be criticized if you weren't broad enough. It was very practical, or a lot of it was practical. It was real-life things. I mean, you could have been in the public health area where you were doing statistics as a major, public health statistics. That wouldn't have been my area.

It was called the administration and planning program in the School of Public Health. It didn't really do that good a job of teaching about administration. They actually did an evaluation a number of years ago, and it didn't really do that good a job on that. But planning was great.

I did take one or two courses at City and Regional Planning. One that I got a B in. That was Fred Collignon's class. Did I tell you this? Fred Collignon got a lot of money from RSA [Rehabilitation Services Administration]. It was a special studies course or something. There were five or six of us in the class: Bob Metts, Judy Taylor, Herb Willsmore, myself, maybe one or two other students. He wanted us to do a paper, but he didn't want us to select what we wanted to do; he wanted us to do a paper that he wanted us to do. I think it was part of the work that he was getting paid to do, which faculty are known to do all the time. They get students to do their research. But I wasn't going to do it. I was just not going to do it. I don't remember if I hated the subject or I was just completely bent out of shape about what we were being told to do, so I wrote a paper about why I wasn't going to do his paper. I got a B. But that was the only B I got, I think, in school. I got maybe an A-, whatever. But I had a good average.

That was the other good thing about graduate school. It was hard to get into Berkeley. We had, like, a hundred students in our program. It was amazingly competitive. But once you were there, you really had to do badly to get dropped. They just basically accepted, okay, now you're here—once I realized that, too, and once I realized in class there were some people that were smarter than me and some things that I was smarter than other people in other places, but basically there was a common area of interest and desire amongst a number of people there. I liked going to class. I liked having discussions. I was always worried about writing papers and things like that. But I did well on those, as a rule. I liked the readings. I just like it.

Now, I was only in school for one year. What was supposed to happen was you were supposed to go to school for a year, do a six-month internship, and then finish six months more. I was supposed to do my internship with a guy named Joe Haffey, who now actually runs the School of Public Health's Foundation. I think it's School of Public Health's Foundation. At that time, there were comprehensive health systems, federally established, and he ran the comprehensive health care system in the Bay Area. So I was actually very interested in going to work there.

Internship opportunity in Washington, D.C.

Heumann: But then Ralf Hotchkiss called me and said there was an opening for a legislative assistant in Senator Williams' office. People were afraid to call me to ask me if I wanted to go because they knew I was in the middle of graduate school and they didn't want me to drop out of graduate school. So I applied for the position there. They had 132 applicants, and I got the job. Because Ralf was friends with Lisa, and I had met Lisa before.

Brown: Lisa?

Heumann: Walker. Anyway, I got the job. The school was good. They said I could take it for six months, so I was only going there for six months. Rehab paid for me to fly out there. I had SSI [Supplemental Security Income]. I shared an apartment with Diane Latin, who I have to call. I just realized that. And lived southwest? I kept getting my IHSS, because I was a student, and I got my SSI. Rehab paid my travel and for the rental of a van and the rental of a driver—payment of a driver. I couldn't have come here otherwise; they had no accessible metro, and I didn't drive.

So I know that Rehab has a problem and doesn't do everything right a lot, but it certainly does things that other programs—I mean, I never would have had this opportunity. They paid when I went to Berkeley. I was a Rehab client. They paid for school. I was out of state. Oh, I know. I also got a Rehab stipend. I don't even know how; I didn't apply for it.

Brown: You mean like a monthly living stipend? Was this in Berkeley or in D.C.?

Heumann: Well, I got it in Berkeley. It was federal. I really don't know how I got it. It wasn't monthly. I don't remember how often it was.

Brown: So it was just money that you had that they gave to you that you could use however you wanted?

Heumann: Right. It wasn't a huge amount of money, but it was helpful, because it was expensive in Berkeley. I didn't buy expensive clothes or anything like that. I never lived expensively. But anyway, school was good.

Favorite classes

Brown: Did you have any other favorite classes? You mentioned epidemiology and—

Heumann: Public health. I took a couple of public health courses. I took—goodness, gracious—I took a class from a woman named Parker. She was great. Primary health care was her course. Then I took a course—oh, my God—who still lives in Berkeley. I actually called him once. I liked the fact that the classes were small. I had never gone to a school—LIU didn't have big classes.

The thing for me that has always been very unfortunate, though, is I've never learned how to use a library.

Brown: Why not? You didn't learn in graduate school?

Heumann: It wasn't accessible.

Brown: Oh. You didn't have to do research papers? Or how did you do them?

Heumann: I just did them. I didn't do a dissertation.

Brown: You didn't have a thesis?

Heumann: I didn't have a thesis to do.

Master's in Public Health

Brown: Did you have to do comprehensive exams?

Heumann: I had to do comprehensives. What actually happened was as it was coming closer to my having to leave, I called Dr. Blum and I said, "Look, this is what I'm working on right now." I was working on IDEA. That's what I was doing in Williams' office. I was working on IDEA; I was working on Section 504 regulations; I was working on transit issues because—he was the chairman of the Labor and Public Welfare Committee—but he was also on the Transit Committee, so I was doing some work with him.

Brown: Let's come back to what you were doing for him.

Heumann: Right, but it was relevant to my staying. What I was able to do was basically make a case that what I was doing was relevant to my degree. So they agreed, but I didn't have to come back. See, what was going on at Berkeley at that time was if you had a science background, you only needed to go to school for one year to get a master's. If you didn't have a science background, you had to go to school for two years. But you needed thirty-nine credits to graduate for a one-year diploma, and I had had thirty-nine credits, so I said, "I've got thirty-nine credits, and I've done well in school." He called back and said what they agreed was I could get my diploma if I took the same comprehensives everybody else did. Now, I don't know if my questions were the same questions, but it was all essay.

Brown: You took that before you went to do your internship? Or you came back?

Heumann: While I was here.

Brown: Oh, while you were doing the internship, you took your comprehensive exams.

Heumann: Right.

Brown: Like by mail?

Heumann: Right. I would have finished school in May, and I didn't leave here till December, so I stayed six months beyond my last—you know what I'm saying? I did a full school year here plus stayed another six or seven months, so I took my comprehensives here.

Brown: It wasn't a very strictly structured program, it doesn't sound like. I mean, it sounds like there was room for flexibility. Did everybody take the same courses, or you got to pretty much choose what you were going to take?

Heumann: We had to pick from categories of classes, and you had to have a certain number of credits from the School of Public Health. I took one or two classes—I think I took two classes from City and Regional Planning—Fred's and some other guy's. I liked that other guy's class. I remember that. I didn't remember what it was, but I remember I liked it. I also remembered I knew it was not the right place for me.

Brown: Oh, the City and Regional Planning?

Heumann: Definitely not.

Brown: But you don't remember how you knew that. Just you knew it?

Heumann: Well, two of the people that lived in the building that I lived in were Judy Taylor and Herb Willsmore, and they were in City and Regional Planning, so I would go up and see them and stuff. That was the other thing, living in this apartment where CIL was for a time, there were just people I could go see. It was easier to be with people. The ability to move around was good.

Brown: Did you teach as part of your program?

Heumann: At Berkeley?

Brown: Yes, when you were in graduate school.

Heumann: No, I wasn't, no.

Brown: How did, if at all, your course work and the reading you had to do for your classes, not including the internship, your course work and your reading, how did that help shape your thinking about disability issues, if at all?

Heumann: Well, it's a little difficult to say because I was doing work with CIL simultaneously. I mean, the way I really defined what I learned in public health is what I was saying, is that it supported my desire to do systems reform and to recognize that things impacted on each other. It gave me a greater level of confidence. You didn't study disability at all. But I *was* studying disability a lot because it was kind of like I was living in a laboratory. I kind of looked at school and the community as one and the same.

Brown: So it was a good fit. It wasn't like you were studying rehab medicine and trying to be working in the independent living movement—

Heumann: Or construction—

Brown: —at the same time.

Heumann: Yes, whatever, yes.

Brown: It was a good fit.

Heumann: It was a good fit.

— 245 —

Daily life as a student

Brown: Did you get along with your fellow students in your program?

Heumann: Yes. I mean, I was friendly with a few people.

Brown: Was it a big program?

Heumann: No, as I said, the whole program was a hundred students.

Brown: That's all. Were there any other disabled students in the program?

Heumann: No.

Brown: Oh, you were the only one.

Heumann: Yes. I probably was the first one, too.

Brown: How was that? Was it a fairly accessible—

Heumann: No. Warren Hall is where it was. It was over by Oxford. It was, like, clear on the other side of campus. You had to get up a very steep hill. They didn't have an accessible bathroom.

Brown: In that building or any of the buildings nearby?

Heumann: Well, I don't know about any of the buildings nearby, but—

Brown: You said you went to PDSP when you had to go.

Heumann: That's right. I needed help. Although I had IHSS, it wasn't enough hours, so it really was good for me in the morning and at night, that type of stuff, but middle of the day stuff, I A) didn't go to the bathroom that much, and B) if I had to go to the bathroom, I went to PDSP because somebody would help me to go the bathroom. Even if there would have been a bathroom accessible up there, there wouldn't have been anybody to help me.

Brown: And just whoever was there would help you?

Heumann: At PDSP?

Brown: Yes.

Heumann: Yes.

Brown: There was an attendant on call or somebody who could help?

Heumann: I didn't need a lot of help, and I knew the people who worked there, so I know people would just help me.

— 246 —

Brown: It wasn't like every time you went in you'd have some new stranger you'd have helping you?

Heumann: No. I mean, it was a good experience in the beginning, just because it did encompass so much. My feelings around the West Coast and the East Coast—the East Coast is heavier; the West Coast is lighter.

Brown: Some would say fluffy.

Heumann: I was going to say airy-fairy, you know? But my mom said to me once, "I knew that it was easy for you to get around in Berkeley or I never would have let you stay there." It's true. It was hard to be away from my family, but on the other hand, it was much easier for me to get around. The weather, while you didn't have the seasons and things, it never got as cold here and never got as warm as here. But, of course, D.C. is not as cold as New York, although New York hasn't been that cold, either, lately, the last couple of years.

Brown: Who can say?

Heumann: Exactly.

Brown: Seventy degrees in November.

Heumann: I liked a lot of the people that I met there, and I liked that a lot of the work was discussion.

Brown: Did you bring up disability issues a lot in class? If you were the only disabled person, obviously you weren't studying it per se, but do you think you raised the awareness of the other students in your classes at all?

Heumann: For some of the students, where we were in more than one class together. Some of the classes, you saw them, but, I mean, I didn't hang out on campus. I hung out at PDSP, so that's the people that I knew more. There are a couple of people, a woman by the name of Ann Cohen, whose name was Ann Tietz, because she was married to Michael Tietz, and—was it her sister? I can't remember this woman's name, but there was somebody else there. No, I didn't really become friends with the students. Sometimes we'd have group projects we'd have to do, so then you'd get to know them for a longer period of time.

We were also on the quarter system. The quarter system was not conducive to making friends. It was, like, get in there, get out. I didn't like quarter system. I survived it all, but didn't feel like it necessarily got as in depth. You covered a lot in a shorter period of time, but I liked it. I really did like graduate school.

Brown: So who were your friends when you were in graduate school? It sounds like it was mostly community folks, not other students. Can you think of some key people?

Heumann: Oh, sure. Ed, Larry Biscamp—the CIL crowd, really. Cathy [Catherine] Caulfield, Carol Fewell—is her last name Carol Fewell? I think it was Carol Fewell.

Brown: You said that was who met you at the airport?

Heumann: Yes.

Brown: But you didn't know her; she was just—

Heumann: I didn't know anybody.

Brown: —coming to meet you there because Ed sent her?

Heumann: She worked at PDSP. No, I didn't know anybody there.

Drug scene at Berkeley

Brown: Tell me about the first—

Heumann: John Hessler I became friends with. Yes, I made a lot of friends.

Brown: Can you talk about the first time you met Ed? Can you remember meeting him?

Heumann: I remember meeting him. I mean, I met him right away. I remember he was in the tank (iron lung), I think, when I met him. I guess because I had polio, it was not a big deal. Well, I did know people who were living in Goldwater [Memorial Hospital]. I knew people who lived in iron lungs, so it wasn't like a big deal thing for me, really. [added during editing: I met Ed on the phone. That was the first time I met him. I spoke with him a number of times after that about CIL and what we were doing in New York with DIA.]

He was very interesting, and, of course, the drug scene out there was pretty intense.

Brown: The drug scene out there was what? Pretty intense?

Heumann: This is not to go out yet.

Brown: You get to decide all that later.

Heumann: What I'm saying now.

Brown: That will help you remember when you're reading it.

Heumann: I was worried about not getting things. But anyway, I had smoked marijuana a few times when I was in college, but Ed definitely smoked a lot more marijuana than I was used to being around. Ed's dog, Tremor, was a German shepherd dog. Ed and Tremor used to be on the street all the time together. I liked being with Ed. We had good times together. It was fun. It was a real sense of freedom that the two of us could just go out, because I had only recently gotten my motorized chair anyway in New York, and still, in New York, I couldn't take the trains, couldn't get to the city, couldn't do a lot of stuff. I'm trying to think. Did they have BART [Bay Area Rapid Transit] then, in the beginning?

Brown: I don't think it was very—

Heumann: Operational yet.

Brown: If it was happening at all. I don't know for sure. Now, were there a lot of curb ramps?

Heumann: They were getting them.

Brown: I was going to say, I didn't think that had quite happened at this point.

Heumann: There were some that were coming in.

Freedom and access at Berkeley

Brown: But the campus was always pretty accessible, getting around?

Heumann: Yes, it was flat. Again, I didn't go into that many buildings. It's much more accessible now, but the undergraduate school that I went to, I had to be pulled up the stairs, and there was a step in the bathroom. Life was pretty relative. In New York, given that there were no curb cuts, I was very accustomed to traveling in the street. Even here, Berkeley was like nothing as far as the traffic was concerned.

Brown: You were saying it was a real sense of freedom for you and Ed to just kind of go off.

Heumann: Exactly, go down the street and just hang out. That was what I liked a lot about Berkeley. It was the sense of freedom and ability to make more choices on my own. I wasn't as restricted by the lack of accessibility. Just the fact that people had vans and lifts and things like that, which I had never—I mean, I had seen them before, but I didn't—I think we used portable ramps in my father's van, is the way I got around with him. That was fun.

I liked the work we were doing. We were working on building CIL. The first year—when I came back, which I know we're not doing today, but—when I came back, then, when I was no longer just on the board and in school, when I was just on staff—that's when I really think I also applied a lot of the things that I had learned in graduate school. The thing about public health for me was it just was generally applicable to life because it reinforced and validated things I believed in and ways of doing work. It was just a very nice automatic fit.

You were studying cases. Even that was fun. Disability would come into the work that was being done and the studying that you were doing, I was doing.

Making friends

Brown: How did you meet people generally? It sounds like since you were right there where CIL was, you might meet people just coming in. Were you at that point—

Heumann: I was on the board, so I met a lot of people through the board because we had a lot of meetings.

Brown: I'm talking about friends. How did you meet?

Heumann: Most of my friends were from CIL. CIL was very different than when you were there.

Brown: I was hardly ever at CIL.

Heumann: Even when you lived there, it wasn't what it was.

Brown: Because it was more—

Heumann: For the first ten years, it was very much the hub of the community. Certainly, when Phil Draper and I were there, we welcomed people in and wanted people in, more than not there. I mean, it is my nature and that was his nature, too. In the beginning, it was a new organization. It was a group of people, some of whom like John Hessler had been around for years. Dick Santos and Larry and them. I mean, John was the director of the Physically Disabled Students' Program at that point. He had been at PDSP for a number of years. I don't know if he went—I guess he went to school at Berkeley. Yes, I think he did go to school at Berkeley. But it was just a different atmosphere.

Brown: I'm wondering if I might be asking a question that, given the reality of what was going on for you, doesn't make a lot of sense, which is just asking about your friends. It sounds like your friends were the people that you were working in the community with, and so it wasn't like work friends and home friends and school friends, that they were kind of all the same thing, except school was separate.

Heumann: I didn't have a lot of friends from school. I never had a lot of friends from school. Just separate friends. I did at LIU. When I was at LIU I did have some friends, but there's only one or two people from college that I still talk to, as opposed to disabled people who I've known over the years.

Brown: But I want to get at those people as well. In terms of your friends relationship, what kinds of things did you do together?

Heumann: Went to the movies.

[Tape 17, Side A]

Heumann: Things were fun with the movies. I guess once in a while we went to restaurants. Went to parties. Did have to study because I was a student. I would go to Ed's house, hung out sometimes with John Hessler.

Brown: Did you used to have a lot of people at your place, like you do now?

Heumann: Nancy was more of the party animal than me. Nancy had a boyfriend, Phil Chavez. Yes, Phil Chavez was Nancy's boyfriend. I really like Phil. Of course, that was fun, when he would sleep over. Phil is a quad—spinal cord injury—and Nancy was a quad from one form of dystrophy, so it was kind of a joke when they would be—oh, Fran. I remember Fran was one of our attendants. She was great.

Brown: Did you say our attendant? Fran was great?

Experience with drugs

Heumann: Yes, we shared attendants. We did, but we didn't share all our attendants. Nancy got up later than I did, so we weren't restricting each other. It's just the way our hours were. But Nancy was more of the party animal. Nancy was more in the drug scene. I was kind of a two to three tokes off a joint. I never like to get out of control, so I was not exactly the kind of person that could do well on smoking joints.

I remember—I guess I was living in—I must have been living in New York. My roommate, Marie, had some hashish, and I smoked a little bit, like one or two tokes, and I was so stoned. I was, like, wasn't coming down, and I was, like, freaking out. I called my brother, "What should I do?" You need to hear Joey say this: "I guess you shouldn't do this again."

Brown: [laughing] Thanks, Joey. How helpful.

Heumann: He, on the other hand, indulged much more than I did.

Brown: So what did you do?

Heumann: Then?

Brown: You just waited?

Heumann: He said, "You've got to just wait it out." Once I ate a brownie that had grass in it. Oh, God, I would never do that again.

Brown: Did you know it was?

Heumann: I did, but I didn't eat a lot.

Brown: You didn't know the effects of it after.

Heumann: I had zippo experience with it. I did it once and never did it again. Did hashish once, never did it again. I could deal sometimes with marijuana because I wouldn't do too much. Ed could just smoke, like, whoa! I was, like, this can't be good for your lungs. I just don't think this is good for your lungs. I also smoked cigarettes at that time, too. When I smoked dope, I was definitely into smoking cigarettes. I liked a little buzz, but don't get me too out of it.

Brown: I don't want to be out of control.

Heumann: No, no, no. On the airplane, on the ground, I like to be in charge. I don't want to think that anybody else can pull the wool over my eyes, so to speak, so I was not exactly a good doper. No. I remember once, when I lived in New York, I had a little bit of grass and I had it hidden in my drawer, and I was taking a shower. My mom was over. I guess my dad had helped me in. My mom was, I guess, going in to get some clothing or something, and she comes into the bathroom [with emphasis] "What...is...this?" I said it was grass that I had picked when I had been at camp, and it reminded me of this boyfriend that I had. "I hope this isn't marijuana." "No, Ma, I wouldn't do that." [chuckling]

But the thing that was so funny is, God knows, it just didn't do a lot of anything, so I don't even know how long it had been there. But she found my birth control pills.

Brown: When was this? In New York?

Heumann: In New York, too. She found my birth control pills. When I was going to Europe, I needed to get my birth controls refilled. She said, "Why are you taking birth control pills?" I said, "The doctor told me to take them to regulate myself." "I hope that you're not doing anything you shouldn't be doing." "Don't worry, Ma. Don't worry." The marijuana one was great, but I do remember that, and, like, oh, my God, she caught my marijuana. What a bold-faced lie! "Well, I hope this isn't marijuana." "Oh, no, Ma, I wouldn't do anything like that."

Brown: Did you ever tell her?

Heumann: No. I mean, I never did it long enough. If I would have been doing it long enough, that would have been a problem. Joey never told her, either. Definitely not.

Brown: Do you think she knew, though?

Heumann: No, no. I never smoked at home. How would she know?

Brown: No, but I'm saying you think your mother really thought that it was grass from the camp that reminded you of your boyfriend?

Heumann: Who knows? She never asked me again. So maybe she clearly thought it might have been, because she said, "I hope this isn't marijuana." But it never rose to the level of worrying about it.

You have to remember my mother had my father teach me the facts of life. She didn't want to do it! That was not the case with most of my friends. Whatever they learned, their mother told them. My father brings in books, and he's explaining all this stuff to me, "This is the body." I remember—in the back room and laughing because I had friends who were a little older than me, so of course I thought I knew everything.

Brown: How old were you when you got this speech?

Heumann: Probably eleven or twelve.

Brown: It's great that he did that, though.

Heumann: Oh, yes. He told me when I was sixteen or seventeen one day—I remember we were in the car, and some friends of theirs daughter had gotten pregnant and hadn't told them. I think I told you this. She had a botched abortion because, you know, abortions weren't legal then. She had been very sick. I remember my father saying to me, "If you ever get pregnant, you come to us right away. We'll help you." I remember thinking, "Pregnant?" I was kind of known as the neck-up girl. That's what my friends called me [chuckling] because I never messed around. I was a heavy maker-outer. That was kind of like the end of it!

But I thought that was really cool. I was sixteen to eighteen. I was young. Had never, ever had that level of a relationship with anybody. But I thought that was really cool, that they were very open to stuff. You always knew that they were there for you, which was very good. You also knew that they wouldn't be happy if you really blew it, so you just knew that if you really blew it, they'd help you out but they wouldn't be very happy about it, so better not do that.

More on social life

Brown: We were talking about things that you did with your friends. The typical hanging out, talking, partying.

Heumann: Yes, that's really what it was. We went to the movies sometimes, dinner every once in a while. I was always busy because I was on committees. Between school and CIL and stuff, I was always busy. As I said, Nancy was the party animal in the house.

Brown: Were you involved in any other extracurricular activities? I'm including CIL, but besides CIL, were you involved with anything?

Heumann: PDSP.

Brown: CIL and PDSP, but, I mean, were you going to services at that point, or were you involved in any women's groups or anything like that, more than PDSP and CIL?

Heumann: I wasn't involved [in] women's organizations. Women's meetings, I went to those. I was on the advisory board for PDSP, and I was on the board for CIL. I was only there—

Brown: A year.

Heumann: Not even a year. I mean, I got there in September and left in June, so it was kind of amazing the amount of stuff I did in such a short period of time. But, you know, it was kind of like kindred spirits with a lot of people there. That was very nice. As long as I hung out with disabled people there, it was good because there I didn't feel like people were superficial. But the nondisabled people, I mean, they were all right.

Brown: But did Berkeley feel—I mean, your first year there—did that feel like any kind of a turning point? I'm not phrasing my question right. The kinds of people with disabilities that you were around, coupled with the freedom that you had to move—

Heumann: The kind of people weren't any different, really, than—

Brown: But I'm saying—did all these things together feel like any kind of an awakening or a turning point or anything like that? Or not?

Heumann: What was an addition to New York for me there was that there was more of a social welfare system. The fact that I was able—the IHSS money wasn't as big a deal, although I certainly couldn't have done it without the money. The IHSS money really added to the dimension for me because in New York I didn't have any attendant help, and neither did any of my friends. Or it was our family. I had some people. I paid some people, but it was very minimal.

Here, people who had more significant disabilities in Berkeley were able to get out and about more independently than friends of mine in the East Coast, so that was all very good because that was really something that I had wanted to be involved with, and it allowed me to learn from it. It allowed me to grow up to the degree that it was the first time that I had more of an ability to make decisions about when I was going to do things. Previously, as kind of now, again—I have more flexibility now than I did in New York in those years because I have more attendant help, but I can't now really just decide to go to New York or decide to take a day off from work without telling Michelle she can't go to school or Saule that she can't go to work.

In Berkeley, because it was smaller, you could ask a friend to come over and help you go to the bathroom. Or there were more people who used attendants who were living closer together. Certainly when I lived in that apartment building, Judy's attendant might have been up there. There were just people around. You could get help from more people. Or PDSP, or CIL, or whatever it was.

But that's one of the limitations on the East Coast. The size makes it more difficult. People don't share because they don't live close enough. Just like Jenny [Kern] and I could share—we didn't share an attendant per se—but if you needed—

Brown: If you had an emergency—

Heumann: Exactly.

Brown: —you could call and I could come over.

Heumann: Exactly. And it was two blocks away.

Comments on UC Berkeley faculty

Brown: Right. I'd like to go back to school for a minute and see if you have anything you'd like to say about the faculty and the program.

Heumann: The faculty were by and large great.

Brown: Who they were—

Heumann: Dr. Duhl, Len Duhl. That was the guy I really liked. Some people didn't like him, but I loved him.

Brown: What did he teach?

Heumann: One of the public health courses I took.

Brown: It wasn't Regional Planning?

Heumann: No. I can remember the face of the guy from Regional Planning, but Len Duhl, Parker—I can't remember her first name—she was great. Dr. Blum. Those were the three that I really liked the most. I had Blum for more than one course.

Brown: Do you have any specific memories or stories of Dr. Blum that you want to put on tape? How you feel about him now?

Heumann: He's a great man. I actually have been thinking about him. He nominated me to be on the community board for Alta Bates Hospital. I remember I felt so honored because, again, I was always living under this delusion that he thought I was very stupid. Then we went on the board of the Over Sixties Health Clinic together. We were on the board together.

Brown: These were all later.

Heumann: Later. But, you know, I just felt very comfortable with him on a certain level. He is a very wise, very smart man. He got disability. I mean, before I came, I think, they had some awareness day that they had sponsored on campus—blind folks, wheelchair—

Brown: He mentioned something about that.

Heumann: He did? What did he say? Oh, I didn't ever tell him I didn't like that. He thought it was a great thing.

Brown: Right. That's what I was going to say.

Heumann: I tried to kind of like once say, "You know, those types of things don't necessarily allow people to be aware." But it was an important thing for him because he was in a wheelchair. I mean, his simulation was in a wheelchair. So that was important.

You need to tell me. So what did he say about me?

Brown: No, he mentioned the simulation exercise, and he thought it was very, very, very useful for him. I just got the sense of him, that he thought you were supportive of that, which obviously, it sounds like, you did think that because you didn't tell him that you didn't think it was such a good idea.

Heumann: Right. What else did he say? What kinds of questions did you ask him? Actually, we did—but this was later on, when I was back at Berkeley, at CIL—Peter Leech got a grant to bring rehab counselors from different parts of the West Coast to come to California for

a week. They each assumed a disability for a couple of days and lived with a disabled person, and then left their disability and spent another one or two days talking about what it was like to have had a temporary disability—which was really more the programs that I liked.

Brown: How was that different from the ones that—

Heumann: I wasn't really a big fan of making somebody temporarily disabled for a short period of time.

Brown: Oh, you mean, the length of time.

Heumann: Yes.

Brown: And also the living with a disabled person?

Heumann: Exactly.

Brown: I think that would make a big difference?

Heumann: Right. That's why I thought it was a good program, because what you had was an opportunity to see the change from being a disabled person, to having a disability, and to be with someone who had adapted to their disability allowed you to recognize that there was a way to do it, even though it may be difficult. I really don't think I was involved in that simulation. Maybe there was another one and I was involved with it, but it certainly was never anything on the top of my hit parade.

[tape interruption]

Financial support while student

Brown: When you first got to Berkeley, how did you find the housing that you got? Do you have any memory of how you looked for it?

Heumann: Oh, just went around and looked. I think Carol [Fewell]—maybe Zona [Roberts]—helped me look.

Brown: Did you find attendants through PDSP or CIL, or through friends?

Heumann: PDSP, not CIL, I don't think.

Brown: Did you use CIL at all when you were on the board? Use the services?

Heumann: I don't remember if I used wheelchair repair. I don't know whether they got the housing list from PDSP or CIL or both. CIL was really new at that point, and PDSP was around for a couple of years already.

Brown: Did you work at all while you were in school? I mean, I know you were on the board, but you didn't get paid for that, right? Did you do anything for paid work?

Heumann: No, because I was on the PDSP committee, I was on the board for CIL, I took a full load of classes. No, I don't think I had a paid position.

Brown: How was your housing paid for? You mentioned that your PA [Personal Assistance] was paid.

Heumann: SSI.

Brown: Oh, SSI paid. So you basically got a lump sum—

Heumann: SSI didn't pay. I had an SSI check. I used it to pay my rent, and then I also had this—

Brown: The Homemaker Chore stuff.

Heumann: Right, which I did not use for anything but my PAS [Personal Assistance Services]. And I had—

Brown: The stipend.

Heumann: The stipend.

Brown: The Rehab stipend. So that's how. I was just curious how you paid for all that. And Rehab obviously bought all your books.

Heumann: Right.

Brown: They flew you out to California, the initial time, you said?

Heumann: I don't remember. I don't remember if they flew me out for the initial flight. I don't. They flew me to Washington for my internship.

Mentors at Berkeley

Brown: Who would you say, if you had to name one or two people, would you say helped shape your thinking on disability issues the most, during the year you were in Berkeley in graduate school?

Heumann: In Berkeley?

Brown: Yes.

Heumann: I think Ed, definitely. We spent a lot of time talking about things. Phil Draper, John Hessler, yes.

— 257 —

Brown: Who would you say were your role models or your mentors in grad school? If you would even use those words.

Heumann: Well, I consider Blum to be a mentor. I don't know if he considers me to be a mentee, but I considered him to be a mentor.

Brown: Is there anything else you'd like to say about your experiences in grad school?

Heumann: I think Ed was a mentor of sorts, when I first came out there.

Brown: In what sense?

Heumann: I think people kind of took me under their wing a little bit when I was just out there.

Brown: In terms of showing you where things were, showing you things locally? I mean, you had already used attendants, right?

Heumann: I never used attendants as extensively, as I said earlier.

Brown: But did they?

Heumann: Yes, well, sure, they all did, so I could talk with them about issues.

Brown: What kinds of issues did you—

Heumann: Hiring issues and when you were having problems, how you dealt with things. Yes, I talked to him about that.

Brown: Do you remember anything specific?

Heumann: No.

Brown: Any more funny stories? I'm interested in funny stories.

Heumann: Too bad they're not around. They'd have their funny stories about me, I'm sure. No. I've run out of my funny stories.

Brown: Funny stories are over.

Heumann: Yes. Funny stories. Sleeping with John Hessler, Larry Biscamp. Those are funny stories. Going over to dinner with John. John slept with a lot of people. John was a quad, a very tall guy, like six-five. That was a funny story.

Brown: Why was it funny?

Sexual Attitude Readjustment Seminars

Heumann: I didn't plan it. It's just kind of unexpected and funny. Oh, oh, I know stuff I did when I was first there. I was involved with the Sexual Attitude Reassessment [SAR] program. Now, that was a big—that's what I was doing with part of my time. Yes, I forgot that. Susan Knight ran it. She had a grant. She had a grant. I don't know if it was from Rehab. I don't know. But UC [University of California] San Francisco School of Medicine had this program where they were training people to work in these programs that they ran. They had like weekend or double-weekend programs, where people would come, talk about sexuality.

They were looking for people to get involved, and I got involved in it. We would do lectures. When I came back, we did more of it, but I know that I had done this in '73 because one of the guys that was in the program—when I was in Washington—he came back to D.C., and I remember spending a night with him.

Brown: You were restructuring your attitudes [chuckling].

Heumann: Right. But that was a very good program. That was California, definitely not New York.

Brown: Tell me what that means.

Heumann: Well, there were a series of things. One is at one of the weekend programs, they would have a panel of disabled people, and we would get up and talk about ourselves, our sexuality, and people could ask questions. They had all kinds of panels.

Brown: These were for everybody?

Heumann: This was primarily a nondisabled audience of people who were coming for one- or two-weekend programs, to talk about sex, their sexuality issues they were having. Then there was also another program within this program where, I guess, we were learning to be facilitators. You had to go through this mopey weekend program, where you learned about sexuality, talked about it.

One of the things we had to do was sexology. We had to work with another person. It could be a person of the same sex or not. Well, we had to do a bunch of things. We had to explore other women's bodies and men's bodies.

Brown: This was with a partner?

Heumann: It was with a small working group.

Brown: So somebody would strip down, and you'd touch him?

Heumann: You wouldn't do it in front of everybody. It was kind of like you and partners, but the partners changed sometimes. Yes, it was basically to get a better understanding of the anatomy of people, which, of course, I had never done. Neither had anybody else there. That was kind of different. [laughter]

— 259 —

Then they would have these "sexoramas." They were basically to desensitize you. They would have, like, multiple screens with all sorts of porno films on them. Don Galloway lived in California at that time. I remember that he was at one of the programs. I can't remember if it was the program in '93 or afterwards, but—

Brown: Ninety-three?

Heumann: Seventy-three. Once in a while I would interpret for a blind person. I think it was for Don, but I did do it more than once. You have to look at all the screens and basically run through them really quickly, and ask, "Which one do you want to hear more about?" And so [chuckling] seventeen people doing it with their dog, doing it with a woman, doing it with a man, doing it with seventeen people.

When you talk to people about it today, they can't even fathom it. I thought it was good for people to be coming together to talk more about sexuality and intimacy, and to learn. There was some good work Susan was doing. From a disability perspective, sexuality has been so narrowly defined, from a nondisabled person's perspective. So really to allow both disabled people and nondisabled people to have a better understanding of what sexuality was all about, and that it wasn't just intercourse, was great.

She actually had some funding and did some films of disabled people with a partner. They were talking at one point—this is when I was at CIL—they wanted to do a film of a disabled woman having a physical, including an internal. They had asked me if I would be willing to do it. I remember thinking yes. I mean, we talked about it, actually, and I did have an interest in politics then already. I was like, I don't really know if a film like this comes out with me—even though it's just for medical purposes, because that's what it was for—up on a table with my legs apart, having someone sticking a speculum—but the speculum.

We had that training in '73. I remember having a speculum put in me so someone could look inside my vagina, and then having a speculum put in somebody else and looking inside another woman at the clitoris and the vulva and the vagina. My brothers and my father would go swimming on Sundays, and it was just for men, and they went nude swimming. That was no big deal. But women never did that. So I never saw another woman. That was the experiences of a lot of the women who were there. Even if you saw each other naked, you never saw the parts that weren't exposed because of the difference in female and male anatomy. But those problems are definitely a thing of the past. I mean, this was part of UC Medical School.

But that was great. I learned a lot in those programs. I'm a pretty sexual person, you know, so for me that was another experience of being able to be more open. It wasn't that it developed into any kind of longer, more intimate relationships, but at that point in my life—

Final thoughts on graduate school year at Berkeley

[Tape 17, Side B]

Heumann: I was involved in other things. I'm just trying to think now. I was also in some discussion group that we had once a week. I think I might have been the only disabled person in it. No, no, no, Maria Albanese was in this, too. It was just kind of a free-floating encounter. Encounter was too strong a term, but it was a self-directed program. I do think that was then. So there was a lot of self-exploration going on. I mean, it was somewhat that I was away from home and no one could check on me or see me, and it was just a very different environment.

I did go to synagogue when I was there. I'm trying to remember. I had to get carried up steps. Hillel had a ramp in the back. I don't remember. But I'm sure I did go because I never missed. But I didn't go on Saturdays. I only went for the High Holidays. I don't know whether I was there for the High Holidays that year, though. School started late. I cannot remember that.

I remember this other group. There was a husband and a wife and another woman, and they were all living together. They would basically swap, so it would be him and her, the other him and her, her and her, and oh, no big deal. Everybody was cool. They didn't stay together after a while. But I was just, like, this doesn't make any sense to me. I mean, I was what one would define as pretty promiscuous in a very quiet way [chuckling], but I was not into that. I was loyal for as long as I was with somebody.

I think '70 to '75, '76 were very important years in my life. I think in part because I didn't have the motorized wheelchair before that, and so those were the years also when I was just learning, wherever I was living, to be more independent and to really be able to explore a little bit more what I was interested in doing because there had been so low expectations. I mean, I was doing lots of stuff, but the reality was I was creating it all as I went along. There really weren't other people with my level of disability that I knew. The Irv Zolas and people like that, who were doing things, were not in the disability community. The Paul Longmores, the Harlan Hahns. They were all in academia or whatever they were doing. They were all more physically independent, but they weren't movement people.

I think those of us who had more significant disabilities tended to come together and were working more on the creation of organizations to make change because the barriers really limited our ability to do so much, so that there was, at least for some of us, real value to be able to come together to share ideas and to recognize a commonality, both in articulation of problems and solutions. It was the first time that you could really—not just in California but in New York also—really be creative and start thinking about what a future could look like and what were the ifs, what did you need to have, and who were they for?

That's why public health was so interesting to me, because that's a lot of what I saw it as. I mean, you could go into narrow things, as I said earlier, in public health, but you could also be very broad and eclectic.

Brown: Anything else you want to say about graduate school in California?

Heumann: No.

Brown: In this tape session?

Heumann: No.

XI. Aide to Senator Williams for Eighteen Months; Master's from UC Berkeley; and Suing National Airlines

Senate job, 1974-1975

[Interview 11: March 22, 1999] [Tape 18, Side A]

Brown: I'd like to start by talking a little bit about the internship which you had with the Senate in '74 and '75.

Heumann: It really wasn't an internship. It was really a regular position. It fulfilled an internship obligation for my graduate degree, but it was a regular legislative assistant position. They knew that I might only stay for a half a year when I took the position.

Brown: What led you to the job then at the Senate?

Heumann: I was working—no, I was in California in graduate school. I needed to do an internship, and I got a call from Ralf Hotchkiss saying that there was a position open in Senator [Harrison] Williams' office and would I be interested in applying.

Brown: What was Ralf doing at the time? How did he know about that job?

Heumann: He lived in Washington.

Brown: Was he working on the Hill?

Heumann: No, but he knew Lisa Walker, who was the staff person who had responsibility for the position. The person was going to work with her. I knew Lisa. Apparently, people thought that I would be a good person for the job but were afraid to call me because they thought that if I knew about the job, I'd leave graduate school and they thought I needed to finish graduate school. So I was basically able to pull it all together and do all of the above.

Brown: Why did they think that you would be a good candidate for this job?

Heumann: It was a job working for Senator Williams. He was the chair of the Labor and Public Welfare Committee, working with Lisa Walker and Nick Edes. He had a substantial responsibility in the disability area. They were working on the development of what was then called the Education for All Handicapped Children's Act. They were working on overseeing what was going on with the 504 regulations. They were doing a number of things that were directly related to disability, so people thought it would be an interesting job for me.

Brown: Did you know the senator at that point?

Heumann: I had met the senator previously. He had spoken at a rally that we had had the year before.

Brown: In New York?

Heumann: Washington.

Brown: Where was he from?

Heumann: New Jersey.

Brown: Did you have to do a formal interview and application process?

Heumann: Yes, and they had 132 applicants. I think I did an interview over the phone.

Brown: With the senator?

Heumann: No, staff. I'm sure I sent my résumé. But they knew me. Anyway, I got the job.

Cramped quarters

Brown: You said that you worked with Lisa Walker. Who else were you working with?

Heumann: I worked with a bunch of people. Lisa Walker, Nick Edes, Pat Marky—primarily with Lisa and Nick. Pat was another legislative assistant. There were a couple of other—a woman named Jackie, a guy named David, and another woman—oh, my goodness, why am I forgetting her name? Joycene, yes.

We all worked in an office which was probably as wide as this room and twice as big as this room. Actually, that might be a little bit of exaggeration. It might have been smaller. It was my desk, and next to my desk was Nick's desk, and next to Nick's desk was—I think it was Jackie's desk, and then there was Joycene's and Pat and Lisa. Lisa and I were across from each other. We had at least a foot between our areas. It was very small. Everyone thought how glamorous it was to work up there, but it was very small.

Brown: Cramped quarters.

Heumann: There was no such thing as a private office. Not at all!

Brown: What was the atmosphere then, fairly chaotic? A lot of noise? A lot of phone calls?

Heumann: It was always very busy because we worked for the committee staff. It was busy. We were not on the same floor as the hearing room. He actually was chair of the Labor and Public Welfare Committee, and he was on the Transportation Committee. I did some work for him also with the Transportation Committee, when he was doing some work on accessible transportation.

I did everything, from answer mail to work on legislative issues. I was learning from them. It was very interesting.

Learning about legislative process

Brown: What did you learn?

Heumann: Just basically how legislation was really made, the process it was made. Learned about hearings, learned about more groups in D.C. that I had worked with previously, did more cross-disability work. I certainly learned more about legislation under IDEA because I came in I guess it was June or July of '73, and I left in December of '75.

Brown: So the Education Act was—

Heumann: The Education for All Handicapped Children's Act.

Brown: When was that?

Heumann: It was November of '75.

Brown: So you were working on getting that legislation together? Or what were your tasks on that?

Heumann: A lot of the work had been done because they had been working on it for a number of years. I was basically working with Lisa and Nick on report language, we were still working on statutory language, and we were also doing work on the Rehab Act. The 504 regs were not out yet. Then I worked on general, miscellaneous other things.

Brown: So it wasn't only disability issues?

Heumann: No. A lot.

Brown: Was it primarily disability?

Heumann: It was primarily disability, but not exclusively.

Brown: When you say "working on," can you give me an idea of what you would do during a day? You would come in and sit at your desk and think of statutory language?

Heumann: No. Lisa was the lead, and I was working with Lisa. It was kind of whatever you were given. We worked on camp legislation [setting standards for camp safety]. It was just a very fast-paced office. I had a number of areas that I did work on. It could be anything from Lisa saying, "This is an issue. Do some more research on it. Do some writing on it." Going to a meeting, talking to other staff people, meeting with groups, doing hearings. It was just a wide array of activities.

Hand-typed letters

Heumann: And mail. Oh, God, the mail. There was so much mail that we had to answer.

Brown: Primarily with form letters?

Heumann: You only did form letters if you had more than a certain number of letters. Otherwise, they had to be individually answered.

Brown: So you would write the letters?

Heumann: Yes, we'd write the letters.

Brown: What was the technology at that point?

Heumann: Typewriters.

Brown: So you had to type them.

Heumann: Right. Without computers, at all. Handwrite them, typewrite them. But it was more that you typed them. In my year and a half there, there was one thing that I wrote that didn't have to get approved. It was ordering a report [chuckling]. I'll never forget that. Otherwise, there was a practice of six or seven people that signed off on it.

Brown: They all had to read your response to make sure—

Heumann: It was accurate. But everybody always had a change. I mean, in the beginning, I really worked very hard to try to make this letter, like, perfect. But then you realized after a while that Lisa saw it, Nick saw it—all these other people saw it. Inevitably, there would be changes. There was never ever a letter that they didn't get a change on it. It's very funny.

Learns federal procedures

Heumann: It was a very good experience because I learned how the Senate worked; I learned about the House; I learned a bit about legislation; I learned about Congress working with the administration; I learned about reg development. I learned a lot. I also learned how advocacy groups help to influence legislation.

Brown: Was it necessarily something you were aware of before?

Heumann: No, I hadn't done a lot of federal work before. Most of the work I had done before was really city- and state-oriented, not federally-oriented. We had the demonstrations, we had the demonstrations in New York around the Rehab Act. We hadn't really worked on the Rehab Act, so I didn't really know a lot about the process.

Brown: Were you the only disabled person working in that office?

Heumann: In that office? Yes.

Brown: Oh, were there a number of other disabled people working on the Hill?

Heumann: There was another disabled guy who worked for Senator Alan Cranston, who was a veteran. Then there was another disabled person who came—oh—the guy who's now senator from Georgia. [Max Cleland]

Brown: Nunn? No.

Heumann: The guy in the wheelchair, triple amputee.

Brown: That guy.

Heumann: We'll remember his name. Anyway, he came to work in the Senate. I think he worked for the Veterans Affairs Committee. Oh, man, his name just left my head again. Anyway, I went over to him in the cafeteria, and I introduced myself to him. I said, "It's great to have somebody else who's disabled here." Oh, the accessibility was not very good.

Brown: I was wondering about that. How did you get around?

Heumann: Rehab paid for a van and a driver, and so the driver picked me up every day from my house and then took me to work, and took me home at night.

Brown: This was just a regular service?

Heumann: No, we rented a van, and I hired a driver.

Brown: Ah, so you could use him whenever you wanted? You would just call and say, "Come pick me up now?"

Heumann: He had another job during the day, I think. But he never left early. I mean, he never left it.

Brown: Long hours?

Heumann: Long hours, yes.

— 268 —

Typical day

Brown: Like what? Do you remember a typical day?

Heumann: I would get there at nine, nine-thirty and leave between six and eight. Definitely never really left before six. Worked sometimes on weekends.

Brown: Some things don't change. Where did you live?

Heumann: Southwest.

Brown: Just in an apartment? Was it hard to find a place? How did you find accessible housing?

Heumann: You know, I don't really remember. I lived with another woman named Diane Latin, who was a friend of mine from the President's Committee. We looked around at a bunch of places. We actually got the apartment building to widen the bathroom door. We had a one-bedroom. Diane slept in the living room. It had a kitchen and a little dining area and one bathroom. I didn't need as much help as I do now. It was very hard to find attendant help.

Brown: What did you do?

Heumann: I found somebody who lived in the building who was from Turkey who helped me, and then there was a woman who was a roommate of the guy who drove for me, who helped. But as I said, I only had those two people.

Brown: What did you do at work? Could you go to the bathroom by yourself at that time?

Heumann: Somebody would help me there, Pat or Joycene, Lisa sometimes. You had people just help.

Brown: You were saying it wasn't very accessible, though.

Heumann: The bathroom wasn't very accessible. I'm trying to remember if they made it accessible when I got there, or if was already—well, quote-unquote "accessible." It was a very weird configuration, and there was not an accessible bathroom on the floor that I worked. You had to go to the fourth floor. It might have been that they already had one there because that was where the hearing room was. It was minimally accessible.

Brown: What building was this?

Heumann: Dirksen. But it was fun. I met Senator Hughes. Joycene used to work for Senator Hughes. Joycene was a beautician before she took this job, so Hughes would come in the office every once in a while, and Joycene would cut his hair. He was a great guy.

Brown: In the office?

Heumann: Behind the office.

Brown: Where was Hughes from?

Heumann: Iowa. He was a recovered alcoholic. A big, burly guy. Met staff—Senator [Joseph] Biden's staff, Senator [Dale] Bumpers' staff. It was a good atmosphere. At that point, I was in my twenties, so there were a lot of younger people working up there. It was a good learning experience. It was also people would come from California, and I would see people from California and New York because they would come by and visit. Diane was, in her own way, a pretty sociable person. We both had international interests. We had actually gone to Australia together. She had gone to Australia. So it was good.

Working for Senator Williams

Heumann: I used a lot of the contacts that I had made in Washington when I went back to work at CIL.

Brown: I'll ask you more about that. Were the senator and his staff pretty aware of disability issues, given that they were working on a number of important ones?

Heumann: Certainly, the staff were. The senator, like any senator, was only so much involved because he had so many things he was involved with. We had this one incident one day. I had been working with people on setting up the American Coalition of Citizens with Disabilities. We had a guy who was working as the director. For some reason, he did an interview with a newspaper from New Jersey that had as its banner headline, "Williams Staffer Key Lobbyist." [chuckling]

I can remember getting a call from the senator's office, telling me about this article. I guess what this guy had done was to basically try to say that ACCD had all these powerful connections, including someone who worked on the staff in Williams' office and basically they could lobby easier [chuckling]. I'm like, okay, this is the end of this job!

Brown: What happened?

Heumann: That was great. They did an interview with Williams, and Williams said that if I was as good as the article said, he was glad I was on his staff [laughing]. I remember we had a meeting with him once with some people from New Jersey on segregated housing, group homes.

It was a very good job. He was a very progressive senator. He had very bushy eyebrows. He was very connected to labor and more of an old-line Democrat.

Brown: What were you going to say about the meeting you had about group homes?

Heumann: Oh, just there was one meeting we had where people from New Jersey wanted to come in and talk to the senator about group homes. I had to write a memo for him, and he'd go to the meeting where the people came and basically, in a polite way, try to explain how we didn't like certain—like, segregation was not necessarily the right way to be going.

Brown: And the people that were meeting him were—

Heumann: From New Jersey.

Brown: —in favor of them?

Heumann: Oh, yes. They were there, asking for support. Well, lukewarm support we were giving them. But that's where I met people like Paul Marchand and Jack Duncan and Joe Owens and people from PVA, Paralyzed Veterans Association, and National Federation of the Blind. I really got to meet a lot of people because the nature of the job regularly meant I had to call people and ask them their opinion on things, things of that nature.

More about Ed Roberts and CIL

Brown: When and why did you return to Berkeley?

Heumann: Ed [Roberts] got a job as the state director of Rehab in September, when [Governor Jerry] Brown had been elected I guess it was in '74. Ed took the job as Rehab director in September of '75 and told me Phil Draper was becoming the executive director, and they wanted me to be the deputy director at CIL. They assured me that I would be leaving and coming back to California to get an $18,000 salary. They had applied for a grant to United Way, which Ed was assured he was going to get. But it probably wouldn't be until January, February—but not to worry about it.

I was on benefits when I worked in the Senate. I was taking my salary and putting it away towards the purchase of a van, and covering other living-related expenses, but a lot of the salary I was earning was going towards a van.

Brown: Is that a PASS [Plan for Achieving Self-Support] plan?

Heumann: Yes.

Brown: They had those then?

Heumann: Yes.

Brown: It wasn't just you saving it?

Heumann: No, it was a PASS plan. So I left my job. I thought, okay, I had worked there a year and a half. Rehab was just going to continue to support me so long there, and the only way I was able to make it was because I had this van that they were paying for and a driver they were paying for. I was paying for the attendants and the rent and the food—basic living expenses. I said okay. It was going to be an increase in salary, and I thought okay, I've learned as much as I need to learn from the Senate. It would be good to go back and work at CIL and be able to do more advocacy, get some more administrative experience.

At that point, going back to teaching was really no longer a serious thought. So I did. I left. Of course, there was no salary. The grant didn't come through. I wound up working for a good number of years for—I don't know. What was I getting? Three or four hundred dollars a month at CIL [chuckling]. Ah, yes. But it was a good job. Ed—he had a good heart. He got a sucker out of it. Certainly didn't get rich off it.

Goes to Washington to learn legislative process

Brown: Now, why did you want to work in Washington?

Heumann: It was a good experience. Legislative issues were something that I was very involved with. I wanted to get more knowledgeable on, so it was a good opportunity to do that.

Brown: Was there any conscious effort on your part, thinking, well, if I want these issues in the disability world to go anywhere, somebody is going to have to know about this stuff and how it works?

Heumann: There was a process of it—

Brown: Or was it more personal?

Heumann: No, I think it was all the above. ACCD [American Coalition of Citizens with Disabilities] was starting. It was an opportunity for me to get back to D.C. to do more work with people there, and it was an opportunity for me to learn more about issues. If I was going to continue to work with groups on influencing legislation, I needed to have a better knowledge of the process, as well as the fact that I was going to be in the middle of it. He was the chair of the committee that did all the authorizing legislation, so you couldn't have been in a better position, from the Congressional side, unless you were in the House equivalent committee. It afforded me a lot of good opportunities.

Originally, as I said, I didn't know I was going to be back there a year and a half. It was okay, I've got a six-month placement. It would be interesting to come back to D.C. and learn more in six months and go back to California and finish my master's.

Brown: Why did you stay longer?

Heumann: Because the job was interesting, and I didn't want to leave. I spoke to my professor, Dr. [Henrik] Blum, and he got permission for me to take the comprehensives and if I passed—it was basically a series of essays—and if I passed those, then they'd give me my degree. I think I had mentioned this before. They had this program that was a two-year master's program, but I had sufficient credits after the first year I was at school, so they basically bent the rules. They gave me the degree.

Brown: That's what counts.

Heumann: But I didn't go to graduation.

Brown: Oh, you didn't?

Heumann: No, I was in Washington, so I couldn't go to graduation.

Brown: What were your political hopes for yourself at that point?

Heumann: I don't know that I had any.

Brown: Because you had mentioned in the last interview about the sexual attitude reassessment, whatever that was—

Heumann: The SAR.

Brown: —and that they had asked if you'd be willing to—

Heumann: Oh, oh, oh, oh. Right, right, right.

Brown: —be an exam person, and you said that you—

Heumann: There was nothing in Washington that I was thinking of, but I've always thought of the possibility of running for political office. Washington also was another opportunity for me to learn from an elected perspective what a job like that would be like. I think that's when I really thought, "I could do this job." the problem has been it has been difficult for me over the years to get as involved in the political arena as is needed, I think, in order to really be able to seriously run for political office.

The access issue has certainly been part of it. But at any rate, it certainly was something I was thinking about at that time, when I thought it wouldn't be good to—using me to do an exam, a GYN exam. That actually came up later, though. That was after I was back in California that that issue came up, I think.

Lack of Personal Assistance Services

Heumann: But it was a very good opportunity for me. I think it was also good because it was allowing me to move different places and to see that I could live in different places, although I was always conscious of services. There was nothing here at that time. If you went through a home agency, it was exorbitant. You had to pay exorbitant amounts of money, and you had to have people for a certain number of hours, even though I didn't need—you had to hire people for four hours. So I never used anybody from an agency. It was ridiculous.

I was lucky enough that between the people I was able to hire and the fact that I wasn't as weak as I am now, I was able to do more.

The Watergate experience

Brown: I'm not sure how to ask this question, but how did the overall experience affect you, of being in Washington?

Heumann: I was here during Watergate. [President Richard M.] Nixon resigned while I was here. I really loved working here, as I've said a million times, because it allowed me to learn more about the process. I respected the process. It allowed me to see what the disability community then and now still doesn't have. It doesn't have an effective voice of disabled people as lobbyists. There are lots of organizations lobbying on disability issues, but there's only a handful of organizations that have disabled people that are lobbying on disability issues. They are typically narrow in their interests.

Some of the blind groups have blind lobbyists. The deaf groups have deaf lobbyists. The veterans—now, the veterans are different. They're more influential. That definitely was true. There were lots of veterans groups. They certainly were in the seventies, when I was there, because it was during Vietnam or the ending of Vietnam—when did Vietnam end?—'72, '3?

[Tape 18, Side B]

Brown: What was it like being here during Watergate?

Heumann: Gosh, I remember watching him resigning on television in the office. What was it like? Well, a lot of people didn't like Nixon. There was something—the retribution was—what sweet retribution? But it was sad, on the other hand, too. I think when those types of things happen, it's sad. The whole thing was strange. But, on the other hand, it was like being in the middle of a mystery. Every day something was coming out, yet you go to work and you continue to do your work.

The Democrats were in control of the House and Senate. We had been dealing back and forth with the administration on various issues. The hearings were going on. Or did the hearings stop? I don't remember. When did he resign, in August? He resigned in August of '75. Then [Gerald] Ford came in. It was definitely an ever-looming part of what was going on for that period of time. Although we just kept doing our work, you were wondering what effect it was going to have on things—just like with this last issue with [President William Jefferson] Clinton. We just went ahead.

You know, in my socializing there was limited—like now—because things were still so inaccessible. I did go to Lisa's house sometimes, but not a lot of people had accessible places. Fred Fay had an accessible place. I spent a lot of time with him. I did a lot of ACCD work while I was here and got to know people like Fred Schreiber from the National Association of the Deaf and Terry O'Rourke and Al Pimental. Diane was friends with them, so I socialized with them somewhat also.

I was still a kid that was kind of going around and finding things. Diane was a much more sophisticated woman. She was definitely more out there. She was into drinking. We'd go to the bar sometimes. We went a number of times to the Dubliner, which was over near the office. The first time I got picked up by a guy, at the Dubliner. It turned out he was a rehab counselor [chuckling]. It's really funny.

Diane was, like, always in with the guys. We'd go out to the bar and she'd be, like, holding court. I'd be there feeling like this mouse compared to her. She was in a chair, too. It was just very different. She was very assertive. She had this long red hair. I think she had a

stronger exterior, or she had a stronger facade. Yes, that was funny. We went there a number of times. They had good music. We liked going there.

What was the name of the guy that drove me? Jeez, I can see him. A tall guy. I can't remember. He was a nice guy, kind of a free spirit. Oh, actually, I know what happened. I had a guy that came with me from California, Chris, who was Ed's attendant. Came out to work for a while. That didn't work out. I hired this other guy.

Brown: He came to drive for you, or do attendant work for you?

Heumann: No, drive.

Brown: I didn't think you used men.

Heumann: No, no, no. He came to drive for me. Then I was looking for this other guy. That's how that worked out, yes. [Through] advertising, I found him, yes.

Senator Williams and ABSCAM

Brown: Did you stay in touch with the senator?

Heumann: The senator actually was indicted. It was ABSCAM. He was the first representative, I think, at the federal level. But at any rate, he was caught on tape taking money from an FBI agent in what was supposed to be some Middle Eastern deal. It was rumored that his wife—he was married, and he left his wife and got married to this woman who used to work for him in the office. She was kind of considered to be a climber and was never satisfied and wanted more money. So anyway, nobody kept in touch with him afterwards.

But I did keep in touch with Lisa and Nick for years. Actually, I've seen Lisa a couple of times since I've been here.

Brown: What is she doing now?

Heumann: She works for an organization of reporters and basically works with reporters in getting them information and training on education issues. She's married now, and she's got a stepdaughter, and she's on the city council of the community that she lives in, a small community. She might even be mayor now. I don't know.

I met people from Children's Defense Fund at that time. Became friends with a guy named Dan[iel] Yohalem and his wife Jane. That was nice. I socialized with them sometimes. Julie Landau met her husband through them. Ann Rosewater I met around that time, or right after that time. Now she works at HHS [Health and Human Services], but she worked for Children's Defense Fund. Then she went to work for George Miller.

I made a lot of friends at that time. The seventies was a very good period of time, especially in the beginning and middle of the seventies.

ACCD developing as political organization

Brown: What do you mean?

Heumann: There were a lot of changes that were going on. You know, you're still definitely coming off of the whole Vietnam era, a more political activism period of time. Even Nixon was more socially responsible than certainly Ronald Reagan. The Democrats had big margins on the House and Senate side. So there were opportunities—there were still, of course, the usual political restrictions.

One of the things that was going on still at that time was that the disability community was less organized then than it is now. We were just really getting involved within the disability community, the real disability community, on legislative issues. A lot of the IDEA work was basically done without the involvement of many disabled people at all, their associations, or the UCPs [United Cerebral Palsy Associations, Inc.] of the world.

ACCD was really trying to develop a voice of disabled people in the city. There was no NCIL [National Council on Independent Living] at that point. That didn't even begin until the latter part of the seventies, when the centers started. I think NCIL might have started in '79 or '80. There was a lot of emerging things going on. Eunice Fiorito was here at that time. I'm trying to think when she came to work for government. She was president of ACCD. Was she president then? No, Al Pimental was president.

But there was a lot going on. Definitely, we were doing a lot of work on the regs at that point, trying to get HEW [U.S. Department of Health, Education and Welfare] at that point to work on getting the regulations developed and getting the meetings held that they needed to get held. I remember we had one or two meetings, really broad. We invited staff to come up from the administration, John Wodatch being one of them, to find out where they were in their process of getting the regulations developed.

In part, that happened because people at ACCD were saying nothing was happening, so we'd pull in the group to meet. It was certainly fair to say that I had some influence over what was going on, but that article was certainly an overblown [chuckling] fantasy not on my part!

Brown: Was it an exciting time?

Heumann: Oh, yes, because there was a lot going on. There was a lot of emerging things happening. You had 504, you had 502. We were working on all of that, actually—all of Title V at that point. Section 501, 502, 503, and 504. We were involved with all of that. Then there was the IDEA activities that were going on. The ACCD, the activities that were going on. CIL was developing. There was a lot happening. Big problems and just basic organizing still going on. The changes going on within the "of-for" organizations.

Brown: What do you mean? Like, struggles within them?

Heumann: Like, ACCD was an organization represented by "of" organizations, not "for" organizations. It was having a slow influence on the role that disabled people needed to play. But it was slow because it had a very limited budget. Then, right now, as I said, the primary heavyweights in disability have not been disabled people.

Brown: Did you meet a lot of other senators or other important political people outside of the disability arena as well?

Heumann: The people that I mentioned to you before. Bumpers and Biden.

Brown: Oh, I thought you said you met their staff.

Heumann: No, I met them also.

Brown: You said that a number of the people that you met—they were good contacts for you later when you went back to CIL.

Heumann: Yes.

Brown: Is there anything else you want to say about that time in Washington? Any other good stories or memories that come crashing in?

Heumann: There was a guy named John Nagel. John was the American Council of the Blind. Neat guy. He was an older man. He had white hair, like a shaggy dog. I remember he came into the office once, and he was telling me this story about how somebody had come up to him and said that she would pray for him so he could see. He said—he was in his sixties at that time—"Look, lady, I'm sixty-some years old. I wouldn't even know what to do if I could see. Don't pray for me." I thought that was the funniest thing.

Unequal support for people with disabilities

Heumann: I met a lot of vets. I used to joke with Jim May, who was then the executive director. I guess that's when I met John Lancaster, too, who worked for P&A [Protection and Advocacy], I think, in Maryland. I used to say to Jim, "Look, Jim, just find me a veteran. It could be a marriage of convenience. But I'll get my attendant money. He'll get additional money from me. I'll take care of the—make sure the house gets cleaned, dinner on the table, could sleep together once in a while if he wanted, but I could get health care, my durable medical equipment, personal assistant services." It was like a fantasy because the amount of money that I really needed, that I would have been able to get.

Brown: As a spouse you would be eligible for that?

Heumann: Sure.

Brown: Wow.

Heumann: I don't know if I would have gotten the full attendant allowance, but he definitely would have gotten money for me, and I guess I just assumed that I'd get the money also. But if

you married someone who was a para, they would get more money than I had. I was sure that we could make it work.

Brown: I like that you threw that in, "I'll sleep with him once in a while."

Heumann: If he wants, exactly. It's a marriage of convenience, whatever. I used to tease him all the time, really. "Can you find me somebody? I'm, like, serious." That's, of course, when I was having my real serious conversations with people on the Senate side, anybody who was willing to listen, about where is the logic that if I was a veteran, I could get all these benefit programs, and I'm a civilian with the same exact level of need—and I had met a guy, I guess, at that point—it was later that I met him, but he was a priest who had been serving as a chaplain and got polio in [the] military. He got the full package of benefits because he was in the military.

I remember working in the IEP [Individualized Education Program] section of the statute. We spent a lot of time talking about it—what it would be, what it should look like. I remember talking and thinking, well, in twenty years all the people who are complaining about this—it will just be a general part of every student's life. Every student will have an IEP because wouldn't every parent want every one of their kids to have an IEP? Maybe in another ten, fifteen years, but it'll happen.

Brown: If you have anything else or any other stories you want to tell about then, I'd be happy to hear them. Otherwise, we can move onto the airplane incident.

Barred from flying without an attendant on National Airlines, 1974

Heumann: The airplane incident happened while I was working there. I was trying to think of the name of the lawyer who represented me. I had gone up to New York for the December break. It was '94—'74, sorry; it was '74. The guy who was working for me had taken me to the airport, put me on the plane, went home, had no problem, flew by myself. Spent, I guess, a week or whatever it was in New York. Then my parents brought me back.

Do you have the article? Let me see it.

Brown: Do you want me to turn it off?

Heumann: Yes.

[tape interruption]

Heumann: There is a funny story. I didn't used to wear shoes to work. Sometimes I would wear socks, and sometimes I would go barefoot. One day I got called in by the senator's personal secretary. She was an older woman with blonde hair. What was her name? Anyway, she said, "Dear, we really love having you working for us, but do you think it could be possible that you could start wearing shoes?" [laughing] I think the reason I didn't wear them: it was so hot that my feet would swell up, and so they hurt. I wore shoes

if I had to, like, to go to a hearing or something, but outside of that, what was the purpose? So I did start wearing shoes.

Brown: Your feet would swell and hurt.

Heumann: I'd take them off when I was up in the office.

Here's my manual chair [shows photograph].

Okay, so I was working for the senator, and I was coming home from New York. I had my ticket, but I had difficulty getting onto the plane. Actually, I was working on a document on my lap—it was a set of draft regulations on airline travel for disabled people. We were commenting on them, about how terrible they were. They were trying to restrict airline travel: where you could sit, you had to travel with someone. But they weren't anything but proposed. There was nothing final about them.

Part of my job was to review them because, as I said, Williams was also on the Transportation Committee. I asked to speak to the supervisor. The supervisor came, and I explained what they were telling me, that I couldn't be traveling alone was not accurate, that I—

Brown: Wait. You said you had trouble getting on the plane, meaning physical trouble getting on, or they weren't going to let you on?

Heumann: They didn't want to let me on the plane.

Brown: What was their reason? Because you were alone or because you were disabled?

Heumann: Because I was disabled and—my parents were there, so they were going to help me on the plane.

[tape interruption]

Heumann: My parents took me to the airport. It took a while. I finally got on the airplane. My parents helped me on the airplane. They left. They boarded everybody on the airplane. These articles don't give everything that happened, but basically they boarded everybody, the plane wasn't going, some guy came on and said he wanted to see my medical note that said I could fly by myself. I said I had no medical note, and he said, well, I had to get somebody who would act as my attendant. I said I didn't need an attendant. The guy next to me said that he would act as my attendant. I said, "Thanks, but I don't want it."

They said they would have a doctor come on the plane and determine whether I could fly by myself.

Brown: This was whether you could fly by yourself for what purpose? So in case of an emergency you could get yourself off the plane? Was that solely what their reasoning was?

Heumann: They actually didn't say that, but they said there was a rule that said I had to have a medical slip which allowed me to travel alone. At the gate, when we were buying the ticket, I don't remember whether they were that clear on that issue, but we did get into it over the regs. I said, "Look, there are no regs. This is just proposed regs. I work for a senator. I know what this is. Here's a document on my lap. You can see this is not a set of regulations." Which is the reason why they ultimately let me on the plane because I knew more than they did.

But then, when this guy came on the plane, he said, "I'll bring a doctor on the plane to get you this medical paper," and I said, "Well, if you would examine everybody on the plane to determine that they can fly by themselves, then you can have somebody examine me. Otherwise, forget it."

Then the airline pilot comes out. He has this book which says, basically, he or she controls the plane, their ship, and that I needed to have somebody as my attendant. I said in case of an emergency, if something happened, I was as likely as anybody else to be injured. There would be a lot of other people on the plane who wouldn't be able to get out of the plane. Why was I being selected out? He was, like, well, we need to do this, blah-blah-blah, or—

Then the next thing is this b-i-i-g guy, b-i-i-g black cop comes in. This gets to be pretty funny, actually. He comes over and he says to me, "Look, the airline wants you to have somebody who'll act as your attendant, and if you don't, we're going to have to take you off the plane." I said, well, I wasn't and he couldn't just take me off the plane. We got into this discussion about he'd have to arrest me.

Removed from plane and under arrest

Heumann: The one thing that I really did wrong was that I didn't ask them to read me my Miranda rights. I said I wouldn't comply, and he said, "Well, you're under arrest." So [chuckling] I thought, Okay, Rosa Parks, here I go. I'm going to jail." I was trying not to cry in the middle of all this because—of course, this is not a little incident. Everybody's on the plane, everybody is trying to leave, I'm not being compliant, everybody is teed off because they want to be able to leave. So they bring another guy on the plane and they lift me up and they put me in the aisle chair. They take me down the plane, the plane door closes, they ask me for my ID.

I give them my American Express card. That's all I had! My Senate ID. They said, no, they wanted more. This was the Port Authority police who had arrested me. I gave them my Senate ID. "Who do you work for?" "Senator Williams." "Senator Harrison Williams?" I remember this so clearly. "Yes." "New Jersey Democrat?" "Yes." They knew who he was. The Port Authority of New Jersey-New York police.

Well, at that point it was, like, I'm sure everybody realized they had made a major mistake, but the plane was gone. There were no other planes going out that night. It also turned out that this guy was a friend of a good friend of ours, who was a cop. So [chuckling] it was just like here I was—at La Guardia Airport—was it La Guardia or Kennedy? What was it? Kennedy. I called my parents, but I also called Malachy McCourt. You know Malachy?

— 280 —

Brown: Talk about it.

Heumann: Malachy has written a book. His brother is the other McCourt, who wrote *Angela's Ashes*. I don't know his brother, but Malachy is married to a woman named Diane, and they had a daughter who was mentally retarded. He worked for WMCA, I think it was, talk show. So I called Malachy. "Malachy, I just got arrested in New York." [laughing]

Then I sued them.

Brown: Well, now, wait. Let's go back. Did they actually take you to a police station and fingerprint you and photograph you?

Heumann: No. I was never really under arrest. They said I was under arrest, but they never booked me.

Brown: Okay.

Heumann: Once they found out who I was, they never took me anywhere. They didn't book me, they didn't fingerprint me. They couldn't get rid of me fast enough. There I was. That was what this whole picture was so funny about. There was not another plane flying out that night. There I was, in this huge Kennedy airport. Basically, there was no one there. I had to get my parents to come back and pick me up. The next day, I went back to Washington on American Airlines.

Judge Sirica throws case out of court

Brown: How did you feel while this was happening?

Heumann: Well, as I was saying, on the plane I was feeling very upset about what was happening, but I wasn't going to bend on it because what they were doing was totally wrong. All I had to say was this man next to me could act as my attendant in the event of an emergency. I wasn't going to do it. All these guys were huge guys. They were six foot, six foot five guys, standing over me, telling me if I didn't do this, if I didn't do that, this and this was going to happen.

Then, of course, the insult to injury was when we did sue the airline—do you have more articles on this?—when we did sue the airline, there was a lawyer who used to work for the senator, who represented me. He took the case on contingency.

Could you cross my foot, please? This one here.

Brown: That's on tape, too.

Heumann: The tape's finished?

Brown: Oh, no. It's almost over. You can probably get in another sentence.

— 281 —

Heumann: Oh. Anyway, we had John Sirica as the judge. Sirica, you know, had handled part of the Nixon case. Sirica said—

[Tape 19, Side A]

Heumann: —that I was a litigious individual and that I had set this whole thing up, and so he threw it out of court. We appealed it, and the appellate division remanded it back to him. He said if we did a jury trial, no matter what they awarded, the case was worth no more than $500. The airline settled out of court for $10,000, which I think was the first settlement of its kind. There is, again, one of these things when you settle, they're not acknowledging guilt per se, but nonetheless they settled. I think I was gone by the time this thing finally resolved itself.

Brown: Gone, meaning—

Heumann: California.

Incident indicative of prejudice

Brown: What did you do with the money?

Heumann: Oh, paid the lawyer and whatever. The lawyer got a decent amount of it. The only money I ever made in my life before I had this job was over lawsuits. Sued Walt Disney when we went for a wedding, when we had that problem there. Got a settlement from them, and different things like that. Never intentionally. I mean, it's like it was hysterical. First of all, even if I had set this thing up with National Airlines—if I was a tester—it was still inappropriate, what they did. But I absolutely did not set anything up. Why would I have gone to the airport, not driving, have my parents leave me, to get thrown off the airplane?

It just really was indicative of the prejudice that existed then. As far as he could tell, I had had the lawsuit against the Board of Ed and I don't remember what else—so that was another good learning experience. But I remember, here I am with fear of flying, the regulations, all these people badgering me, my desperately trying not to cry in the middle of all this—like, desperately. And I didn't. Getting arrested and thinking, Okay, this is going to be great. They're going to take me to jail, and I'm going to get fingerprinted. We're finally going to be able to deal with this problem, only for them to say, "Oh, forget it. Made a mistake. We're not doing anything. Goodbye. Hope you can get home okay." [chuckling]

Brown: You were almost crying because you were scared or sad or—?

Heumann: I think it was all the above. I certainly was angry by what was happening, and I really felt it was like Mutt and Jeff or Samson and—who was—what's the analogy I want? Samson and Goliath.

Brown: David and Goliath?

Heumann: David and Goliath, okay. David and Goliath. But I didn't even feel like David. A little bit, but—so it was once again feeling like I was making the right statement, taking the right position—Samson and Delilah; David and Goliath—oh, God. Really thinking, Okay, something is going to come out of this. Rosa Parks wouldn't sit where she was supposed to sit; I wouldn't let them do to me what they tried to do on the airplane. We were going to finally get a good position on this for the disability community.

It was funny, though, when I took out my American Express card. It could have been an ad, you know? My neighbor had gotten me an American Express card when I had first gone to Europe, this credit card that nobody could get, but he worked at American Express and he got me the credit card! "Now, that's not enough. You have to show us ID." I was sitting in this stupid aisle chair as all this was going on.

Brown: Oh, you weren't even in the seat.

Heumann: No, they had lifted me up and put me on the aisle chair, taken me off the plane. My wheelchair wasn't back up yet.

Brown: Where was your chair?

Heumann: Under the plane.

Brown: They were going to get it off the plane for you.

Heumann: Yes.

Parental support

Brown: How did your parents react to the whole thing?

Heumann: Oh, just another thing with Judy.

Brown: [chuckling]

Heumann: They were upset, of course, but—

Brown: They supported you, though. They thought you did the right thing.

Heumann: Oh, sure. Yes, that was never an issue with them. They got used to it.

Brown: Now, in the clippings, this senator comes across as being very supportive.

Heumann: Oh, yes, definitely.

Regulations never get signed

Brown: Did that help with the regulations that you were working on?

Heumann: They never got finalized.

Brown: Oh, the ones you were working on never did.

Heumann: No, they never got what they wanted on them. We opposed them, as did a lot of other groups.

Brown: When did the regulations change on that? Do you know?

Heumann: Air Carrier Access Act.

Brown: When was that?

Heumann: Eighties, mid-eighties.

Brown: Did you have any part in that?

Heumann: Yes, we did some stuff.

Brown: Didn't you do some sort of testifying?

Heumann: No, I don't think I testified. I don't think so. We did some stuff with it, for WID [World Institute on Disability] then.

Deals with issues at the moment

Brown: Is there anything else you want to say about your brush with the law?

Heumann: No. That wasn't my first brush with the law, but it was just another incident. It's the kind of thing where it could have been a non-incident if all I would have said was okay, but it was the kind of thing where I just have always believed you have to deal with it when you're in it.

That reminds me. I have to make sure that we file a complaint with US Air.

Brown: That you have to—

Heumann: You have to deal with it at the moment. My experience is that if you don't deal with it at the moment, it doesn't get dealt with. Maybe there are other people that are better at it than I am, but I'm, like, you're there, deal with it. But there I am, no shoes. Marilyn, I think her name was, the senator's person.

— 284 —

Brown: Anything else you want to say about your time in Washington? Any other good stories?

Heumann: No, just that I made a lot of long-standing friendships, I learned a lot, it was a very invaluable experience. I will always be glad I did it.

Brown: Did you ever have any inkling that you might someday be in the position you're in now in D.C.?

Heumann: Oh, no, because there wasn't a position like this when I was there then.

Brown: But that you would be in charge of regs and testifying and following legislation.

Heumann: Not at that point. If somebody would have asked me if that's something I'd be interested in, I don't think I would have thought it was beyond the realm of possibilities.

Brown: All right. Anything else? Or we'll turn it off.

Heumann: Okay, that's great.

— 285 —

XII. Member of Board of Directors of Center for Independent Living; CIL Growth from 1973 to 1980; Appointment as Deputy Director

Earliest memories of the Center for Independent Living

[Interview 12: April 20, 1999] [Tape 20, Side A]

Brown: All right, so we're talking about the Berkeley Center for Independent Living. My first question to you about that is: what's your earliest memory of being at CIL?

Heumann: When I moved to Berkeley and I lived on Haste Street, their office—I believe their office was on Haste Street. Do you have the listings of the addresses of when they were there?

Brown: I only knew that they were at University and then up on Telegraph.

Heumann: Right. I think it went from Haste to University to Telegraph. I lived on Haste Street, in the same building that they had their offices in. They had—what was the question? My first recollection. That it was a very grass-rootsy kind of place. It was good that it was in the building that I lived in because—I was in school, but I could also go down there and just talk to people.

I got on the board, like, pretty early on when I was out there. People like Jerry Wolf and Bill McGregor, who was the bookkeeper, who had no experience, and Phil Draper and Dick Santos and Larry Biscamp and Jan[et] McEwen[-Brown] and Hale Zukas. Those were many of the people who were involved. It was different but similar to what I had been doing in New York—different because it was service focused and similar because it was civil rights oriented. It was nice to go hang out there.

Brown: Were there a lot of people hanging out? Was it that kind of a place?

Heumann: I think CIL became more of a place that people came to when we moved to the Telegraph office.

Brown: Do you remember the University office?

Heumann: You know—hold on.

Brown: Hold on?

Heumann: Yes.

Brown: You're going to call someone?

Heumann: [dial tone] I am. [sound of dialing]

Brown: I'm leaving this on because I think this is indicative of Judy—

Heumann: [sound of ringing] It was kind of a muddle for me because I went to CIL—[sound of ringing]—I mean, I was at Berkeley from, like, September till May or June, and then I left, and I went to Washington.

Leon: Hello. [Joan Leon answers phone]

Heumann: Joan.

Leon: Yes.

Heumann: This is Judy and Susan, and we're on tape because she's doing my oral history. I'm trying to figure something out. When I moved to Berkeley, you weren't yet working at CIL, were you?

Leon: I don't remember you when I first—no.

Heumann: No, because I was there in '73. When did you get there?

Leon: I got there a little after that, but in '73. I don't think that you were—as far as I know—

Heumann: When did you get there in '73?

Leon: Probably in May. It may have been June.

Heumann: Did I get there in '72, or I was there in '73, '74?

Leon: I think you came and visited and started school. I don't think our paths crossed, for some reason.

Heumann: Ed [Roberts] was not the director when I was there, was he? No.

Leon: Oka-a-y.

Heumann: Wait. I lived on Haste Street, and the office was on Haste Street. Did it go from Haste Street to University?

Leon: Yes.

— 287 —

Heumann: Okay, it went from Haste Street to University, and when you worked for Ed, you worked on University Avenue.

Leon: Right.

Heumann: Right. I left CIL around May, June of '74.

Leon: No, you couldn't have. Didn't you start Cal in September of '73?

Heumann: I started Cal in September of '73, and I left at the end of May or June to go do my internship in Washington.

Leon: Oh, of course.

Heumann: So I was still a Cal student because I was doing my residency, but then I was gone for a year and a half. I thought that you came on after. You sure you didn't come on there in '74?

Leon: Let me—

Heumann: I think so. Because Ed was not the director while I was there. Ed became the director after I left, I'm pretty sure.

Leon: Well, you know, I'm not terribly good on dates.

Heumann: But it was Haste Street and then University.

Leon: Yes. Hale would have had—well, let me pull up my résumé—because I came to town, I worked in San Francisco, and I didn't come to work at CIL until—let me see here. [chuckles] It's funny, isn't it? It's so hard for me to remember back that far.

Heumann: I know. Do you have your résumé there?

Leon: Yes, but, see, I came to Berkeley in 1972. Yes, I guess I must have started with CIL in '74.

Heumann: Yes, I think that's right. Yes, and I think that's why we didn't really know each other very well.

Leon: No, I didn't know you at all. I knew of you, but I didn't know you.

Heumann: Right.

Leon: I don't know if you ever saw me, but I don't remember that.

Heumann: You went up to Sacramento when? To work for Ed.

Leon: Well, I have down here '77.

Heumann: That's right. So we worked together when I came back in '75, December of '75.

— 288 —

Leon: You didn't come back to CIL, as far as I recall, until we moved onto Telegraph Avenue.

Heumann: That's right. I was never really at the University Avenue office because I left in June-ish of '74, and I came back in December of '75. I went to the office on University Avenue when I would come back and stuff because I remember going up in the elevator, and I remember being upstairs. Ed was the director then, but Ed was never the director when I was there.

Leon: Oh, okay. Who was the director?

Heumann: I think—you know, at one point it was Larry Biscamp and then it was Dick Santos, and it might have been Dick Santos and then Larry Biscamp, or Larry Biscamp and Dick Santos. But it was the two of them who were—and John Hessler was the chair of the board.

Leon: I see.

Early board members

Heumann: Jan McEwen was on the board, and Hale was on the board, and Ed was on the board.

Leon: He was?

Heumann: I believe so. Ed was on the board. Cathy [Cathrine] Caulfield, I think, was on the board.

Leon: Well, then, that would be important to add, to put in here.

Heumann: I think so.

Leon: I think you should put that in. I don't know any of that at all. I also don't know—

Heumann: Phil was on the board, Phil Draper. I think Phil was on the board. Yes, I'm pretty sure.

Leon: What a group. It never left. It was really the group that remained—

Heumann: Well, John Hessler was the director of the Disabled Students' Program. He was the director of the board of CIL. Susan was asking me what's my first recollection. I think the best question to me was what's my first recollection of Berkeley because I lived in the building with CIL, but I actually also spent a fair amount of time at DSP, because I was a student and I needed to use the bathroom at DSP, so I'd go over there. I'd hang out over there and have lunch with people there and go to Top Dog and all that kind of stuff. Then after school I would go over to CIL and we'd have meetings and whatever. It was just, like, get acclimated to the community. By the time I got a little acclimated to the community, I was gone again.

— 289 —

Recruiting by Ed Roberts

Leon: Well, Ed used to say that he recruited you.

Heumann: He did recruit me.

Brown: Yes, we got this. We can tell you later, off tape, Joan.

Leon: Okay, okay. You stayed at Zona's.

Heumann: When I was there?

Leon: Because that's what I—

Heumann: In the very beginning—no, I stayed at Zona's when I first got there, and then we found a place on Haste Street. Zona and Ed's because Ed was there. Then when I came back in '75, I thought I stayed at Zona's again.

Leon: You may have.

Heumann: But was Ed still there?

Leon: Yes.

Heumann: Yes, he was.

Leon: Yes. He was there until he went to Sacramento.

Heumann: But he was in Sacramento when I came back.

Leon: No, no, no. You were working at CIL. We overlapped at CIL for at least two years.

Heumann: No—you and I did, but Ed didn't. Uh-uh, not Ed. No, no, no. Ed was gone. No, Ed was gone. Because you went up there to work with Ed after he was there for a couple of years. No, Ed was gone. Ed got sworn in in September of '75, and I left in December because Ed had told me—he basically asked me if I wanted to be the deputy director. I don't really recall that there was a real—

Leon: I remember. I remember that discussion.

Heumann: Yes, there wasn't a real search or anything.

Leon: No, no, no. We were involved with putting in the right people when Ed left.

Heumann: Exactly. There was a grant that had been applied for, to United Way, and Ed and Phil, in talking to me about this job, had told me that this $18,000 salary was a guarantee and that I could come back and start working. It wouldn't start until February or March, and then when I got back, they didn't get the grant. So that was my introduction into living on SSI.

Brown: Welcome to CIL [laughs].

Leon: Well, it was good experience.

Heumann: Yes! Well, I survived it. I wasn't worse for wear. All right, thanks.

Leon: Good, I'm glad you're working on your oral history, you two.

Brown: Hang on one second.

[tape interruption]

Learns from the disability community

Heumann: I think what's interesting for me is we had lots of political discussions, both at DSP and at CIL, so it was part of my educational experience, so to speak, because everything was so easy to get to. While I did a lot of that in New York, it was different out here, maybe because it was a more academic crowd on a certain level and it was a more working-class crowd in New York, even though numbers of the people had gone to college, but it was people who were in college or people who were working. New York is just a much more driven kind of a place, California, the Bay Area, is more laid back.

It was after the Free Speech Movement, so I wasn't linked up in any of that, and it was also an opportunity for me to explore. The development of an organization, where we were both developing the structure of the organization—the management-related issues—that had some money, where getting money was a clear purpose of the organization, to run programs, as well as to be able to have serious discussions on issues like housing and what was our philosophy about housing and what was our philosophy about transportation.

In a lot of ways, I think a number of times I was more of a purist on some of these issues, but also there wasn't a lot of difference of opinion. In the beginning, CIL was an organization that was cross-disability but primarily in the area of blindness and physical disability, although there was Hale in the middle of all this—someone with a very significant language disability. It was people mixing it up in their own ways.

John Hessler, this kind of magnificent guy in his stature—he's, like, very tall. John was, like, six-five, -six or -seven. Just even in the equipment that people used, there was a lot of adaptations in their wheelchairs.

Things that I remember about Berkeley in the beginning: going to Phil Chavez's house, and I can't remember, quite frankly, if it was in '73 or '74 or when I came back in '76. But being at his apartment, where he had this big container with this very big, thick plastic straw that was hung in such a way that he could get it—he's a quad—and he could drink his water, and he drank water a lot. It wasn't cold water. That's really when—I started drinking warm water when I was out there because Phil drank warm water, John Hessler drank

warm water, Phil Chavez drank warm water, lots of people drank warm water. Judy Taylor drank warm water—

Brown: You just needed to fit in.

Heumann: Well, it's just that I needed to see that—yes, I guess. I don't know if all those people would have drunk their water warm independently of each other or whether there was this momentum. Of course, we never discussed it. But those types of things, which nobody ever really thinks about. I don't know why Phil Chavez's place strikes me the most. But then when I think about other people's places, they had very similar kinds of setups.

Discussions clarify policy and advocacy issues

Heumann: It was a time in the beginning where we—well, for me, it was the ability to think about issues that I knew and concerns that I had, and to begin to start talking about how to develop services and how to do advocacy at the same time. So it was like not only addressing the problem of housing—because CIL did have housing lists, and they did have the personal assistant services list—it wasn't just looking at the policy problems around housing; it was actually looking at how to help people who needed housing get the housing they needed, at the same time that you were having to overcome all the barriers of accessibility and discrimination to get housing.

What I liked about CIL is that I like to have a lot of balls up in the air at the same time. So when creating that organization—I came in—the organization was incorporated. They had a little bit of money. I was not the first round of people there. But I was close enough, I think, that I had a real influence on the development.

But they had already done things like had serious discussions about why CIL should not be a housing program.

Brown: You mean a housing program of people living there.

Heumann: Right. They were very clear that—they'd had these discussions. We continued to have the discussions over the years, but in the formulation of the organization the founders really had thought about issues and needs that people had at the same time that they had made decisions that housing development, segregated housing, was not what they wanted to do. That, I remember thinking, was great.

Brown: I want to go back to something that you said a little bit ago. You said that on a lot of these issues you were more of a purist than other people. What did you mean by that?

Heumann: Well, if we can muddle our dates and not stay in '73 linearly, it was a time—see, when I left Berkeley, I stayed on the board.

Brown: When you went to D.C.

Heumann: When I went to Washington, I stayed on the board. I think I actually stayed on the board the whole time. While I didn't attend most of the meetings in person, I did attend some meetings over the phone. I'm trying to remember. I guess this actually might have been while I was back again, not on the phone.

Segregated versus integrated services

Heumann: But there was work that was being done on CIL providing transportation services. We had something that we called the Pumpkin, the big orange—well, it was like a mail truck, kind of. Anyway, we did transportation with that. We actually had a driver. We might have had another vehicle. But we were seriously considering twelve or fifteen vehicles. The board had actually approved it. This was, I think, probably the only time that Phil and I really disagreed. I pushed a re-vote because my recollection was that I felt very, very strongly that if we were going to really fight for accessible transportation, we couldn't be deterred by running a system that was A) going to give us a bad name, because you could never meet the transportation needs, so then you would become the enemy of the disability community. It wouldn't be seen as trying to help make something very bad a little bit better while you were trying to make the system, itself, accessible.

So, we in the end either canceled the order or didn't go forward with the order for the vehicles. I felt that was very, very important because I really thought it was going to take us off the track, and I thought it was inconsistent with the policy decision that the organization had made earlier on housing, which was that we spend our time and our energy on making systems change and not getting muddled in a quagmire, you know, of politics and services that—

It wasn't that I was opposed to services because I definitely believe very strongly in services. Personally, I think services in many cases should be a strong component of a center. What I really valued when I came to Berkeley from New York was that there was this ability to combine politics and services, but that the services were controlled by disabled individuals, so the purpose, the design, and the implementation of the services were designed by those of us who needed it.

In New York, it was always a problem because our politics might have been stronger, but we were very much stuck because we frequently couldn't do things that we wanted to do, particularly with people who had more significant disabilities, because we didn't have the means to get there, the ability to get people out of their houses.

Brown: It almost sounds as though your issue was the segregation because you didn't want the housing or the transportation to be segregated programs; there should be advocacy to make those systems integrated, whereas, like, attendant referral—it would be a little more difficult to have that be a mainstream program because the people that need it tend to be people with disabilities.

Heumann: Right, exactly. On issues like housing and transportation, to me, it was that the system had a responsibility to make those programs integrated and accessible for all people. That didn't mean that we didn't need a housing service that fought on policy issues, state laws, federal laws, and then the most basic of issues: dealing with actually helping people obtain accessible housing, modifying housing, working with tenants, helping disabled people learn about what it meant to rent a place, what their rights were—all that was very much something I saw as a part of a center—but just not running the program.

So fighting for accessible transportation was definitely something that the center needed to be involved with. Even having a little bit of transportation, which could help us get people here and there but wasn't, like, really the lifeblood or never would have been the lifeblood—if we could have run a lifeblood system, it would have been different—but kind of a sporadic system. So I think it did allow us to fight harder for transportation because we didn't have any false illusions that this smaller system was really accommodating our needs.

First experiences hiring attendants

Heumann: But when I first came to Berkeley, also, what—tell me if we talked about this—the issue for me was using attendants. Did we talk about this?

Brown: I think so. Tell me a little bit more about where you're going.

Heumann: When I first had to start interviewing attendants to decide when I wanted them to come in and what I wanted them to be doing—

Brown: This doesn't sound familiar. This is interesting.

Heumann: I really had never had that opportunity. I received SSI and I received IHSS.

Brown: This was when you were first there for school?

Heumann: Yes. I applied for it when I got there. I started applying for programs that I needed, and then got my SSI, I got my IHSS—I got my IHSS retro[actively]. You apply for it and a number of months later got it, and then you got back from the day you applied, the amount of money you should have gotten.

But knowing, okay, you were going to get X number of hours, how to use those X number of hours. I mean, there was the basics. I had to have somebody get me up in the morning, and I needed to have somebody help me go to bed at night, and then patch it together during the day so I could go to the bathroom. But it was also what did I want them to do for me, or with me. I never really was in a situation where I had the ability to truly interview and select and direct because until I went to college, my mother provided all my personal assistant services. Even while I was in college, during the summers and on the weekends, my mother did my personal assistant services work.

When I was at college, I had a very minimalist program. It was a roommate that helped me with the basics and then friends who helped me with the rest. So I was very used to not having what I needed. Because I was younger at that point, I could wait to go to the bathroom for seven to nine hours. I could do that even when I first got there at CIL.

So the ability to have people to talk to about how you screen people and what you want them to do, and if they're not doing what you want them to do, how to deal with that—those were all very important things for me. The ability to talk to people who had those same experiences. I think that probably, for me, was the most personal peer support as well as—actually, Greg Sanders helped me with my applying for my SSI and my IHSS. He actually went with me for one of my interviews.

Brown: Was he CIL? You were using CIL services to do this?

Heumann: Yes.

Brown: In terms of talking to people about attendants and stuff like that, did you go to a formal support group?

Heumann: No.

Brown: Or it just happened while people were hanging out?

Heumann: Well, a lot of the people who were my friends used attendant services.

Brown: So it was just informal.

Heumann: Right. I never went to a [support group]. There wasn't one at that time. I mean, there was. It was every day, every place you went if you chose to be in those circles of people. Then I had a roommate, Nancy D'Angelo, and she used an attendant also. She had been in the same situation as I had previously, and her mother and sister had done all her attendant work. So we were also able to talk about things in the house. Then she had a boyfriend who was a quad, Phil Chavez, and we could talk about it with him.

But I remember talking to Ed about it, and I remember talking to John Hessler about it. Judy Taylor and Herb Willsmore because they lived in the building that I lived in, which was also great—to be able to have access to disabled people so quickly was great. It was also a real learning experience for me because I didn't have my motorized wheelchair until I was, like, twenty-one or twenty-two years old.

Real independence for first time

Heumann: So here I was, twenty-five years old, and on a certain level I would describe myself as being, like, three—maybe eight. But, you know, I never had, like, independence, like real independence to do things by myself. My sense of direction was even worse then than now, and getting places by myself—I needed not to deviate too much from the path.

Going from my house to campus, to classes, by myself was a big deal because also the undergraduate school I had gone to was literally one square block. You didn't go across the street. That was the entire campus. You went across the street to the restaurant—not the cafeteria, but to the restaurant.

— 295 —

So there were all these things that were going on for me: being away from my family, West Coast, different food, roommate—my roommate was a good friend of mine from New York who—I had decided there was no way that I was going to California by myself, and we kind of suckered each other into going.

She kind of started getting into the wild side of life pretty quickly, actually. It was this being in school with people that I was interested in. Being in graduate school, for me, was great. It felt much less confining. It wasn't because I had selected this program that I was dying to get into because we'd talked about how I got into the program. It wasn't that at all. I mean, hell, I kind of groped my way along. Public help? What is this?

But it was this natural fit. It was, like, a divine—what do I want to say?—

[Tape 20, Side B]

Heumann: Anyway, it did feel like a divine intervention on some very real level. I missed my friends and I missed my family, but it really felt like—I certainly missed New York—I hated the artificiality of California, but it was a manageable size for me. Even though the transportation wasn't accessible, here were all these people that had accessible vans. I mean, I'd never really seen any individual who had an accessible van. There were van services—you know, the van service that picked me up to go to work every day when I was a teacher in New York, but I didn't know anybody who had a van. All my friends at that point had cars, which I couldn't get into.

Here there were lots of them. People were getting support from Rehab, which—it as a much more intimate, close community in certain ways. I think it really was, as I said earlier, an opportunity for me to start thinking differently. In New York, I was the president of the organization. I was starting all these things, but here I could kind of step back a little bit and be reflective—but still pretty aggressive—in a community that was going through similar experiences, I think.

The radical world of Berkeley

Brown: It's funny because it almost sounds as though you had the same experience that a lot of young disabled people have when they move to Berkeley, which is, like, wow, I can go places and I'm not that weird. Just the world sort of opens up for them. I've seen it happen to a lot of people. It sounds like the same thing sort of happened for you.

Heumann: I didn't feel weird. For me, what was different about Berkeley than New York, because of the size of the community, was that you saw people more frequently. Nothing to do with disability. But if you had a disability, you were more apparent on the street. In New York, you were a percentage in a much bigger pie, even though the percentage was the same; and because the geographical area was bigger, it was less likely you'd run—you didn't just, like, walk all over the city, you know? You'd walk over an area. I could walk for blocks and blocks and blocks in Brooklyn and never see any of my friends who had disabilities. That wasn't true here. People lived in your building, they lived around the corner, they lived a couple of blocks away.

— 296 —

At that point already, Berkeley was—1973, '74—there was ten years of activity that had been going on between Cowell Hospital and the dorms. So from that perspective of the community, a lot of stuff had gone on before I got there. Just that energy. Here was this very radical community. I remember—and I guess I don't want names necessarily used around—

Brown: You can block it out later.

Heumann: You know, when we were trying to get the city to make things accessible, for as radical a community as it was, you couldn't just go in there and say, "Look, let's be real. It doesn't make sense that all these streets have curbs on them. Let's just agree that we'll make the city accessible and we'll do it in X number of years, and we'll work on it." It wasn't like that at all.

There was a lot of work that people had to do, a lot of meetings, a lot of persuading, make sure you had a lot of people at City Hall to demand that this happen. To me, that was so very interesting, that here you had this radical Free Speech Movement of people who couldn't quite get that we had a right to be able to get across the street without putting up a big argument.

Brown: You mean the people in the government.

Heumann: Yes, in city government. Even though they—again, it was smaller, manageable. You could get people to leave their homes, and they had motorized chairs and they could pretty much walk to City Hall from—people didn't live in the hills, so it wasn't like you were trying to get them—that's not where people lived. So you could get large numbers of people to meetings. It was more difficult to get them to Oakland, if you had to get them to a supervisors' meeting, until the BART was accessible—things of that nature—but there was, to me, this image that nondisabled people were nondisabled people, even if they're radicals or liberals. They still don't necessarily get the issues.

I think, though, that because the disability community was becoming more active in that period of time, '73 through—you know, the '70s—'73, '5, '6, '7—when I was there—as people were running for City Council positions, they did know that they should say what involvement they had in the forming of CIL or supporting CIL because CIL people voted, and we registered people to vote. We very much saw that as being an important part of what went on, that we tried to be a political force within the community.

Terrible sense of direction

Brown: I wanted you to go back to something else because I know all about this, but just for future historians, you mentioned your bad sense of direction. If you could just say a few words about that and then we can go back to CIL memories.

Heumann: Really, I had never gone anyplace by myself until I was, like, twenty-one or twenty-two years old. I always had somebody pushing the chair or driving the car. So I never really paid attention to things. I think I also didn't feel like I was in charge, so I could agree with

somebody that I was with that we were going to go [to] X place, but it wasn't usual—again, I was walking—if you think about New York, you never walk that far, so the person that was pushing me typically knew where we were going, so they weren't about to say, "Well, which way would you like to go?" I just kind of went with whatever.

Brown: So—

Heumann: So now I am better than I was at that point in time because I just do many more things by myself. But if I would say, "Go left," it was more often that I should go right. That's still true. Go right; I should go left. But I used to get very nervous also about—like, I wouldn't go into a shopping mall by myself.

Brown: Because?

Heumann: Because I was afraid of getting lost. I would go places where I could clearly see, like, a straight line of—repeat—go [to] the same place the same way. I was not like a big explorer of, "Well, let's turn to the left and come around the corner another way." That made me very nervous because I was always afraid of what would happen if I got lost.

I actually—this was years later—gosh, could have been '79 or '80—where I was going to a shopping mall with a friend, and the person wanted to go off and do some shopping by themselves, and I was afraid to be in the mall by myself. So we had this agreement that we would meet in a certain place—we would go off by ourselves for thirty minutes and we'd meet again in that place in thirty minutes.

I did it, but I was terrified. It's not that I took an elevator and I went to another floor. Spatially, I just don't see things, I think, like some people see them. North, south, east, west—I have no idea what that means. I mean, I do if—in my house in California, my bedroom faced the east because I know the sun comes up in the east, so I can kind of think about Regent Street in Berkeley and the streets around it and keep thinking about the sun, I can kind of figure out where east is and west is. But "meet me on the west side of the street"? I'm, like, what are you talking about?

But this day that I did my thirty-minute stint by myself, I remember, like, making myself leave the spot—because I could have just as easily sat there for thirty minutes; nobody would have known—but it was, like, honor. I was honest. I remember I went into—it was the mall in Kensington? No, not in Berkeley. There wasn't a shopping mall in Berkeley.

Brown: In Richmond, like Hilltop?

Heumann: Hilltop Mall. You could go into all these little stores. But then there was Macy's. I thought, I've got to go into Macy's. It was like playing, like pretending that I was going into Macy's to buy something, but I was just really trying to see could I kind of work my way around Macy's and get back out the way that I needed to go? I got lost. Or at least I thought I got lost. I mean, you couldn't have really gotten lost. But then I realized that I could ask somebody. I said to somebody, "I'm trying to get so-and-so." So they said, "Oh, just go there." Then I realized you can ask people those kinds of questions. I had never really done that.

— 298 —

Age at onset of disability creates differences

Heumann: So I think for many years, really many years, I was learning things that people—even a lot of the disabled people in Berkeley—most of them had been disabled only as young adults or adults, so one of the interesting things about the CIL experience was when we began to mix the group of older disabled individuals with people who had become disabled when we were younger, there were very different experiences that the older people couldn't even relate to.

Quads didn't relate to special education. They didn't have a clue of what it was. They didn't understand—the fact that they weren't supportive—but they didn't really understand some of these issues because a lot of these guys had become disabled driving. They were drinking and driving and doing these kinds of things. We had never driven.

So that's my direction.

CIL on Haste Street

Brown: Okay. Now, going back to CIL and the Haste Street office, which is the one it sounds like you remember better than University, but you can kind of extrapolate—generally, if you would go there, there would be a lot of people?

Heumann: It was certainly not like Telegraph. The Telegraph Avenue office, when I worked there, was a very, very high-energy place, and lots of people were there all the time, not just the staff. The atmosphere now is so very different than when I worked there.

Haste Street was an apartment.

Brown: O-h-h.

Heumann: The Haste Street office was in an apartment building, and so yes, people did come and hang out, but you didn't have, like, the open space to be able to do what you could do on Telegraph Avenue. I assume that more people hung out on University Avenue because it was bigger space. On University Avenue, to the best of my recollection—I didn't go there very often—they had a larger defined wheelchair repair program. They did some wheelchair repair on Haste Street, but there wasn't that much room, but they did do it.

Wheelchair repair, again, like personal assistant services, like housing assistance, like financial advocacy, was for core services that people needed. You needed wheelchair repair services in those days more than you do now because chairs broke down more. You could be up there a fair amount of time to get your wheelchair fixed, and they were getting involved. I don't know if they were doing Medi-Cal billing yet or they were just trying to get a Medi-Cal system set up.

You had an apartment, it wasn't on the first floor—I don't think it was on the first floor. I think you had to take an elevator. You know, marijuana was kind of a big thing. I had never done mari—no, I had smoked a little bit of marijuana in college and a little bit in my apartment in New York, but I was blown away by the volume of marijuana and—really, it was just marijuana and hashish, hash, that people smoked. But it was more marijuana, really.

I think in those days people were not really—I didn't know if they were doing coke or other stuff. I wasn't friends with those people. But some of those people could put away the grass, like, whoof! Me, it was kind of this joke because I could, like, take a toke and I was afraid. I didn't like to get stoned. I didn't want to be out of control. I was not into kind of like floating in space [chuckles]. I was actually not a very good person in that area. But it would be funny to watch other people just kind of smoking a lot in different places.

That was the other thing. People could smoke on the street. It was just very different than a New York atmosphere.

Brown: So that atmosphere in the actual office that you remember—this sounds fairly casual?

Heumann: Oh, very casual.

Brown: Friendly?

Heumann: Yes, it was very casual, it was very friendly, it was very informal. People had desks and places to work and there were places to go, but it was small. The organization was really just developing. It outgrew that space pretty quickly.

Brown: So in terms of equipment and facilities, were things kind of patched together? There wasn't a lot of stuff?

Heumann: The kind of stuff you used in the seventies anyway was different than what you use in the nineties. So no, there were no computers. There were typewriters, there were desks. Everybody didn't have a typewriter, to the best of my knowledge. There were telephones. That type of stuff was there. We had a meeting room, a room that we met in. I remember we had board meetings.

Early client process

Brown: In those early years, most of the people who came to CIL, were they already a part of CIL? How did people that weren't really a part of it—how did they find out about it?

Heumann: I think when people came into town, like myself—because I wasn't a part of it—you became a part of it. Not everybody was a part of it. But really, in the beginning, there wasn't a lot of money, there wasn't a lot of stuff happening. We were serving relatively large numbers of people, given the size of the organization, but I think it was word of mouth. I don't think in '73—there would be some articles in the paper, but there wasn't a lot of outreach in the beginning. It really was word of mouth.

It was also disabled students leaving school, coming into the community, and it was, like, the Phil Drapers of the world who couldn't get services at DSP who were coming, who were involved in setting it up, in setting up CIL. So you had that mixture of people. It was over the years that we started to be working with people who wouldn't be there all the time. But as I said, certainly everybody in the beginning wasn't hanging out there all the time. They weren't part of the in-crowd or whatever you would say.

I mean, I came as an outsider, and Nancy came as an outsider, and we weren't outsiders.

Brown: Did the people become official CIL clients?

Heumann: They became a member of CIL. I think the membership was pretty soon. I think to run for the board, definitely—I think you had to pay dues. You had to be disabled. There were different rules about that.

Brown: To be a member or to be on the board?

Heumann: You had to have a percentage of people on the board who had disabilities. Nondisabled people could vote. I don't remember the rule around how that went. You'd have to have a percentage of disabled people on the board, yes.

Brown: So how did someone become a CIL client? Not everyone was a member. I thought a lot of people weren't members. Am I confused?

Heumann: You know, in the beginning it wasn't that formal. How did you become a client? You just came in and said you needed something. There was no federal money. There was no state money. There was no system. It was over the course of the years that we started—I don't even know when the intake forms came in. They might have been in the beginning. There was money from the San Francisco Foundation, so there were some requirements, but it was certainly not as formalized. You became a client because you came in and said, "Can you help me find housing?" or "I need an attendant" or "Can you help me with my benefits or wheelchair?" You didn't question people if they said they needed something, if they said they had a disability.

Board membership and elections

Heumann: The membership stuff—I remember later on, issues around—there was some time in the organization where we were trying to decide whether it would be a self-perpetuating board.

Brown: What do you mean, self-perpetuating board?

Heumann: Whether it would be elected by membership or the board would elect itself.

Brown: What happened?

Heumann: I have to think about this. I'll think about it. It was definitely later on in the history of the organization.

Brown: We can come back to that.

Heumann: Do you have minutes, or do they have minutes for all the board meetings?

Brown: I don't know. I mean, I don't.

Heumann: I think they lost a lot of stuff. It's a shame.

Brown: Well, is there anything else you'd like to say about—

Heumann: The beginning years there?

Brown: Yes, early years, before we get into the board issues—not issues, but your being on the board.

Heumann: I mean, we can talk about being on the board now. It all was kind of together. Because I came out with the explicit purpose of going to school and getting involved with CIL, I was nominated and elected to the board, but it wasn't, as I recall—the competition wasn't fierce.

Brown: So what was the actual process?

Heumann: I don't know.

Brown: You don't remember? But you think you had to have been a member before you could be on the board?

Heumann: Yes, I think you had to be a member. You paid ten bucks or five bucks or whatever it was, and you were a member. You had a disability, so—

Brown: I thought I read somewhere that two people had to—

Heumann: Nominate you? That might be true.

Brown: You don't remember that.

Heumann: It sounds familiar. No, that might have been for nondisabled people. That's how they may have done it around nondisabled people. I don't think a nondisabled person could just be a voting member, I think. But I don't think that was true for disabled people. I don't think you needed signatures as a disabled person. You might have needed signatures to run for the board. That might have been. But there was something about nondisabled people that I'm remembering, and that might have been it.

Brown: So how did you become a member of the board?

Heumann: Whatever the process was! I was there, I was involved, and I was doing a lot of stuff from the very beginning, and I was asked to run for the board, and I did. I think there were times when they had elections.

Brown: Was it members that voted for the board, as far as you can recall?

Heumann: Yes, yes, the members voted for the board.

More on composition of board of CIL

Brown: You said earlier, on the phone with Joan, some of the other people that were on the board. How big was it? Do you remember about how many people?

Heumann: I want to say twelve to fifteen, ten to fifteen.

Brown: You were pretty sure that Ed and Phil and Hale—

Heumann: Yes, and John Hessler and Jan McEwen and I think Cathy Caulfield was on the board. Judy and actually Herb. I don't remember. They might have been on the board, too.

Brown: Were they all disabled? Were there any nondisabled people on the board that you remember?

Heumann: There was always, like, one or two. I remember Phil Neumark was—I don't remember the timing. Phil Neumark might have been on the board. Ralph Abascal at one point was definitely on the board. That was in the latter part of the seventies. Herbert Leibowitz. No, I don't think he was on the board because he was giving us technical assistance from RSA [Rehabilitation Services Administration] regional office. But he was involved, for sure, a lot.

Brown: Was there other kinds of diversity regarding disability type or gender or minorities?

Heumann: There was blindness and Hale and quads and polios. Race wasn't an issue at that point, really. There were no deaf people involved. But it was a cross-disability board.

Brown: What do you mean race wasn't an issue? There weren't any people of color, or nobody talked about it?

Heumann: The original CIL group was a pretty—I mean, the Berkeley community was a pretty white community. The disabled students themselves were a pretty white group in the early seventies. So looking at '73 and '74, I think Ron Washington at some point got involved, but that was afterwards. I don't think that was in '73, '74. Deafness didn't become an issue until after I got back there in '76, really. Certainly, issues around people with cognitive disabilities didn't become an issue until after '77, either for psychiatric disabilities or people with cognitive disabilities.

Brown: What about gender? What was the gender breakdown? It sounded mostly male.

Heumann: Cathy, Jan, maybe Judy—there were more men than women, but there were a reasonable number of women.

Brown: You said John Hessler was the chair?

Heumann: Yes. He as the director of—

Brown: PDSP.

Heumann: Yes.

Ms. Heumann's strengths on the board

Brown: What strengths do you think you brought to the board?

Heumann: Commitment to work. I had experiences as an individual whose disability had occurred when I was young. No, I think Jan also, actually, became blind—I'm not sure if she was born blind, but she certainly was blind when she was young. But I think I really pushed more the issue of—this is not in '73, '74—it was more when I finally got onto staff, but it was really more looking at, serving a broader age range of people and a broader cross-disability group.

I think I had experience in having worked in DIA. I certainly had experience because of my lawsuit in New York in organizing because of what we had done with DIA. I had experience with the media because of what we had done around the lawsuit. I was a reasonably friendly person. Liked to work with lots of different types of people. Yes, those types of things.

Brown: What role did the board play in the organization at that point?

Heumann: The board and the organization were very closely aligned in the beginning. The board gave direction to staff. They voted on things and directed on things that needed to happen. I don't remember so much of the specifics, but we definitely kept minutes, had motions, did voting. The director of the organization would come and present issues. That type of stuff.

I'm hungry.

Brown: This tape is almost done, so—

Heumann: Let's finish.

Brown: Did you play a particular role on the board?

Heumann: I don't remember. You mean was I an officer?

Brown: Yes.

Heumann: I want to say yes, but I can't swear to it. I wasn't the chair.

Brown: Right.

Heumann: Yes, I was a very active member of the board. I mean, I was in school at the same time, so I was doing school and the CIL board, and I was on the DSP board also. They didn't call it a board. It was their advisory committee, but I was on that also.

Brown: Was there a lot of the same people on both?

Heumann: There was some crossover but not completely, at all.

No limits to what CIL could do

[Tape 21, Side A]

Brown: So what direction did you see CIL going in when you started working with them on the board?

Heumann: It was a group of empowered, relatively young people who believed in the beginning that we could continue to make a difference, and so it was positive, energized, future-looking but not too futuristic because [chuckles] it was kind of a one-day-at-a-time putting it together. There weren't other models that you could look back on and say, "Oh, let's look at what this group did in the past and see where they went." Particularly in '73 and '74, at least for me—I mean, I was thinking of what could happen because that's when I began—well, I already had been doing this. I had been doing it in New York, thinking about if I could create a system, what it would look like. So this was another level of being involved in both creating something that was direct for people and also doing systems reform work.

I don't think I felt there was a limit to what it could do. I also don't think that we recognized the potential that it completely had because funding was very limited. We were trying to figure out how to get funding. There were very few opportunities at that point. There was no federal or state independent living money. I think the first federal grant that CIL got was in '75. They did a national conference on independent living, the first national conference. It was at the Claremont.

They might have also had a peer support grant where they were looking at: what impact services for more significantly disabled people had on people becoming more independent. I think it was around that time. Sue Stoddard was involved with it, from BPA [Berkeley Planning Associates].

— 305 —

Vision for CIL

Brown: What was your vision for CIL at that point, when you were first on the board? Or your goal?

Heumann: Just to keep working with it and keep creating and developing and trying to see how far we could go. I had more ideas by the time I got back, when I came back in '75. I had lots and lots of ideas of things to do because I had enough time to be there, see it, learn from it. I was helping to create, but it was also a very big time for learning and taking things in. Then when I came back as the deputy and I'd been in Washington for a year and a half, and I'd now had my New York and California experiences and my legislative experiences, to me, at that point, there was no limit to what we could do.

I probably am one of the few that think it is very unfortunate that CIL broke up in the eighties, when they had all the financial problems.

Brown: Broke up, meaning?

Heumann: Well, Computer Technology Program, the Kids Project, DREDF. Those were all CIL programs. What I was interested in creating was an organization where disabled people could come and get a full spectrum of things, everything from working on civic-related issues—policy issues—curb cuts to transportation to fighting for money for IHSS to housing services and VISTA. I mean, it was very—when I got to CIL, there were fifty staff, when I came back to work on the staff. At our high point, we had two hundred staff.

The organization had this crisis over $100,000, and it really made me feel very much that here you had this organization that was really proving so much of what society said wrong, because we were really working with people with significant disabilities at that point. We were getting people out of state institutions for the mentally retarded. We had deaf services that were going in and getting deaf, mentally retarded—so-called mentally retarded—people—in some cases with physical disabilities—out of institutions.

Doing stuff that was totally unheard of in the nondisabled community, let alone here was this group of renegades. Degrees weren't of importance. They weren't looked upon negatively because I think we viewed them as giving us experience that was of benefit, but as far as the actual work was concerned, one of the most important parts of what we were doing—for me—was really analyzing myself and what I saw that I thought would benefit me. Then talking to other people.

It wasn't a selfish thing. It was just really having—for me—to really look at what were the varieties of barriers that I faced in my life, which were attitudinal and had a psychological effect on me and my ability to respond, react. Then had this opportunity to be with all these other people who were basically incredible creative people, and we were very committed people. I mean, it was like this machine that—you know, not for everybody but for a very significant number of us, we were on a real mission. It wasn't a defined—you didn't kind of like enter it per se, but it was just that—I define it as being in a candy store.

Different commitment of dreamers and non-dreamers

Heumann: For me, because I really like planning and I like building on things, like looking at the potential and keeping on looking forward, forward, forward, there were a lot more things that I felt we could have done. Eventually—and I'm jumping around, but—eventually there really became this conflict of people who couldn't dream, in my personal view, beyond a very limited way.

Then this group of nondisabled people who were not committed to the issues. I mean, it's not that they weren't committed; it's not that they didn't do good work; but in the end the organization didn't mean the same to them because they could leave the organization and get another job, and their life didn't depend on the organization.

I think that was very hard for me, to see that going on. I remember thinking, when we were in the strike days, which was later on in the seventies, early eighties, you know, talking to people and thinking a black organization would never have something like this going on. It just wouldn't have happened. A minority organization at that stage of development would not have had what was going on. It was a group of people who had very extreme political views. I would never say that it wasn't a hardship. I think the financial problems that the organization was going through was a hardship for many people.

Common thread of discrimination

Heumann: I was living on two hundred bucks a month plus my benefits. At that point, I was out of school, I finished my stipends. I didn't have a lot of money. I had my SSI, my attendant services, and my two hundred bucks a month. But I think like, we just kept creating. It was who was left out? Then you'd kind of look around. Okay, deaf people came and they wanted us to set up a program, but there was a deaf program in the community already, so, well, should we be setting up a deaf program?

One of the people who had come asking for it was a guy who was a quad or a triplegic, Dale Dahl. Dale wasn't getting what he needed in the regular deaf organization. So we set up an advisory committee, we did a study, we did all these different things—because our goal at that point was certainly not to go after another deaf organization, but it was hey, people are saying they need something from us that they're not getting, and one of the things that some people wanted was this cross-disability issue to be dealt with, for people to work together.

We were seeing that there was a value in working together. There was a common thread of discrimination. There were different interventions that people may need. You know, a deaf person might need one thing, and a blind person another, and a person with a physical disability something else. But in the end, it was discrimination, and in the end, it was feeling like—for me—being together with people and working together and learning from each other was really helping to create something different.

Phenomenal organization between 1973 and 1980

Heumann: What the organization did between '73 and '80 was so phenomenal. We created children's programs, we had substance abuse programs—we had a substance abuse program, where we had people with substance abuse working with people who had—no, the problem I was thinking about is we had this peer mentoring program for kids. We had this project where Zona Roberts worked doing peer support with parents, and we had kids with disabilities who were being given peer support by adults with disabilities.

I mean, stuff that was totally really unheard of. We had to fight with agencies to get money, but if they came and looked at us—outside of the financial stuff—you could not help but be totally blown away by the type of people who were there, coming in and out, and how accessible it was and how we were so much a part of the community of change, and we were working in coalitions—the transportation work that was going on, the coalitions around the county when Prop 13 came in. We were becoming—I mean, two hundred employees—a 200-person organization in the city of Berkeley was a major corporation.

But it never was kind of viewed that way. There wasn't anyone who really came to our aid and said, "Okay, we'll give you the $100,000." There was never any question of misappropriation of funding. We had a very nice guy who started out doing the bookkeeping, who wasn't a bookkeeper, who had a drinking problem. They just kept him on. By the time we got an accountant to come in, there were a lot of problems already in place, and it was like trying to catch up.

But I remember when Bette McMuldren and I wrote the grant for what was the Disability Law Resource Center, which later became DREDF, there was a CETA [Community Employment Training Act] grant. We put a project together in a couple of days. The peer support work that was going on—as we began to get people coming in for services who had really more significant disabilities, the whole peer counseling program had to change. It had to become more sophisticated because people had a certain level of experience but didn't have another level of experience. Being able to get someone from the community who was a psychologist or a psychiatrist who could come in and talk with staff, to allow staff to increase their skills as they were working in those types of projects, and make sure that we were really responsibly working with people.

Inclusion of parents and kids

Heumann: So at the same time that we had this service system that was going on, we were working like crazy on transportation and Medi-Cal and IHSS and all these other issues. I mean, 504 certainly. We were so very involved with that. Even IDEA. I mean, we got this grant—when we got the Disability Law Resource Center money, that's when we brought the parents into the organization.

There was some real opposition about bringing parents into the organization. Some of the disabled adults did not want parents. It was particularly the disabled people who had been disabled when they were younger who didn't want parents involved.

We were the first center to have a job development program. We had eight or ten people on staff at one point doing job development, job placement. We were doing better job development, job placement than many other places—Computer Technology Program, the Kids Project. I mean, the Kids Project was a phenomenal project. We got money from the federal government; we did training of teachers separately from kids because we were able to get a philosophy—it was difficult to get the school to buy into it, but they did it. They allowed us to do ten weeks of training for teachers because our theory was these teachers are biased; they're not going to be able to appropriately instruct these kids, so we'll teach the teachers so that they could then maybe later at least do a better job of teaching the kids, and at the same time we'll work with the kids.

We did a pre- and post-test on the kids. It was one of the first and only research projects—no, CIL did some other research projects—but that research project was very interesting because we did see that there was a statistically significant change in the attitudes of kids who went through the training, who were below the fourth grade, and for the same program for kids in the fourth through sixth grade, there was no statistically significant change. That was a very important little piece of information that you have to get the kids before they're what?—nine years old, in order to really effectuate change, at least for a minute in time, because you don't know how long it held on.

It was just very, very, very impressive. There was such high energy there. I mean, I've never experienced anything like it again. I don't think I ever will. I mean, I think on a certain level, what was going on at that time was that there were so many problems that you could put your finger on a hundred things and make a little difference. Then the more you did, the more you needed—well, some people felt you needed to start specializing.

We were definitely, from '76 on, doing more work in the area of race. That was slowly happening.

Brown: We'll talk about that.

Heumann: But you really had this amazing coalition which was developing of disabled people, of parents, of younger kids, of people with various types of disabilities. Then, of course, the work that was going on in the van shop—at that point, we got a van shop and the wheelchair repair program went beyond just wheelchair repair but wheelchair design. Because we didn't have the business sense, stuff got ripped off because they designed this great wheelchair that was totally cutting edge that people took stuff from and went off and did things with that we never were able to financially benefit from.

Brown: You mean, ripped off the ideas.

Heumann: Yes. But they were great. I mean, it was amazing. Earl and Tom and—what was his name?—Gary. Kind of amazing. It really was. Randy, Jack, Zona—Through the Looking Glass started at CIL. I mean, it's really phenomenal the programs that—the Computer Technology Program, DREDF, the Kids Project, Through the Looking Glass.

Fiscal agent for BORP

Brown: BORP [Bay Area Outreach Recreational Program]?

Heumann: No, BORP did not—

Brown: It didn't?

Heumann: Nope. BORP was separate. BORP was never part of CIL. CIL might have been a fiscal agent for it.

Brown: They're in the newsletter.

Heumann: But they were never part of CIL, no.

Brown: Maybe they just advertised or let other people know what they were doing.

Heumann: No, they were never—

Brown: I didn't think they were, but that they were in the staff monthly every single time.

Heumann: It might have been because of activities, but they had a separate board. I think we were a fiscal agent for them at one point.

Brown: Maybe that's why.

Heumann: But they were never part of us. Then you had BORP going on. BORP did great stuff. I don't know where they are today. They're still there, but—yes.

More about the board of directors, a cohesive group

Brown: How often did the board meet? Do you remember?

Heumann: Different amounts of time. I think once a month.

Brown: You were in school the first year.

Heumann: First year.

Brown: First year. Then you were in Washington for a year and a half, and you were still on the board. How much time were you really able to put into it? How did you do it?

Heumann: I don't remember. I went to all the meetings when I was in California. I went to all the meetings.

Brown: You said you did some meetings by phone?

Heumann: When I was in Washington.

Brown: Were you able to stay active? I mean, how did you stay informed of what was going on?

Heumann: When I was in Washington? I talked to people. I always talk to people a lot. Clearly, I wasn't as active a board member when I was away, but I was away and so it was kind of like dispensation. They let me be doing what I was doing—because I was coming back, so there wasn't a question about that.

Brown: You always knew that you would be coming [back]?

Heumann: Well, I was finishing—the way it first started, when I left California, I was only going to do a six-month residency, so I was going to be back in six months, in the beginning.

Brown: Were you intending to come back and stay on the board, or were you intending to come back and become a staff member?

Heumann: I don't know. You're much too specific about things. I have no idea. Things are just evolving.

Brown: You just knew you'd be going back to California.

Heumann: Well, I was supposed to go back to finish my degree. If they would have made me follow what they said they were going to make me do, everybody had to do a six-month residency, so I would have come back in January of '75, and I would have done another six months of school, so I would have had to be back.

Brown: And probably stayed on the board.

Heumann: Oh, for sure, yes. I was an organizational person. I mean, I was with DIA and then CIL. There was never any thought of my not being on the board or not being involved in some way.

Brown: Are there any big issues you remember dealing with when you were on the board?

Heumann: I really can't remember. In '73, '74—then I was—after '76 basically I wasn't on the board anymore, and then there were big issues that came up, you know?

Brown: Yes, we'll go into—.

Heumann: No, nothing—I'd have to look at the notes.

Brown: Do you remember there being any tensions or disagreements, or was it a fairly compatible group that had pretty similar philosophy?

Heumann: There always were tensions and differences amongst some people, and cliques. But basically, it was a pretty cohesive group. Some people hung out with some people more than others, but I don't remember, like, big fights or anything in '73 or '74.

Brown: What did you like about being on the board?

Heumann: Being with a group of people that I had common interests with and learning from people and sharing ideas and creating. I liked all that. People who cared about people. People who worked hard. They also played. That was interesting.

Brown: Say more about that.

Heumann: We had some good parties. God, I remember going to this one party where they had brownies that had dope [marijuana] in them. I got so stoned. I hadn't eaten very much of it. I couldn't believe I could not get unstoned. Just felt like I was getting more and more stoned with each minute, which dragged on and on and on. You know, a lot of the people were very nice people.

Brown: Were you friends with a lot of people on the board?

Heumann: Yes. I was friendly with everyone on the board. I didn't ever really socialize with Jan McEwen and the guy who later became her husband—I can't remember his name. But I certainly did with Ed and John and Hale and I think Cathy. She was on the board. I definitely socialized with Cathy Caulfield and Judy and Herb Willsmore. Yes, I socialized with a lot of people there. I had a lot of friends.

Brown: What, if anything, was hard for you about being on the board?

Heumann: Nothing.

Reflections on CIL past and present

Brown: So what's a good question to ask? Is there anything else you'd like to say about being on the board? Anything else you can remember about it?

Heumann: You know, I've been on so many boards in my life that [chuckles] it's like—it was a new board. It was an evolving board. Issues came up more with the board later on, as more complicated things started to develop, but in the beginning, you know, we didn't have very much. There might have been some conflicts that came up. Sure, there were, but nothing that really—I mean, when I think about those days kind of overall, I try not to think—it's hard for me sometimes to go back to CIL because it's so different than it was then. It's hard to be in the same building and remember—you know, looking around.

Size of CIL in the 1970s

Heumann: We owned—well, first of all, we owned the building. Then they had to sell it and then buy it back again. But the property that we had—you weren't there then, so you didn't even know, but—okay, you know there's the CIL building, and then there's all those stores—the bakery and—well, those stores were not there at all. In the back there was a parking lot. The whole area was a parking lot, plus—

Brown: Like Uncle Ralph's?

Heumann: There was none of that.

Brown: But I mean that's where you're talking about, that whole section?

Heumann: That whole area. There was parking, and then there was a long building in the back, which is where they had van shop and the wheelchair repair program. Then there was a portable—we had two portables. There was a portable against the wall of Gorman's—

Brown: That furniture place?

Heumann: Yes, there was a portable there. Then there was a portable by the steps—you know, in back of the building. That beautiful mural that was done? That mural was done by students.

Brown: CIL students?

Heumann: No, students in a class on campus, I think. But there had to be people from—no, I think they were students from the university. But they were real people in that mural—Mary Ann Hiserman and Phil Chavez and Phil Draper and Ed Roberts and all these people. It was great. Hale Zukas. I hope they restore it. Such a great mural. Such a real historic piece, you know?

Then—you know where the bagel place used to be across the street from CIL? We owned that—we rented that. Then you know where—okay—you know there's the wooden doors? Across the street from Uncle Ralph's. It used to be an aerobics place. You go in the back—there was a whole huge office area that we had there, too. So we had all that space in the back, we had that bagel place, we had CIL, we had all that other, and two portables. We had the Computer Technology Program.

Brown: Which was?

Heumann: Which was on Milvia, across diagonally from where it is now, in VISTA. It wasn't part of VISTA, but it was in the VISTA building.

Brown: Wow.

Heumann: It was amazing. I mean, it really was amazing.

Brown: What was that?

Heumann: That growth between 1975—as I say, when I got there in '75, there were fifty people and until 1980 there were two hundred. I just had a great time there. To me, the more creative you were, the more—we had our VISTA programs—really, we had—Michael Daniels—do you remember Michael Daniels? You didn't know him. Well, Michael Daniels runs a homeless project now, which also split off from CIL. But that didn't come till later. He was a VISTA worker. Loni Hancock—Loni was the regional VISTA person under the Carter administration. She called me one day, and she said, "Would you take this guy Michael? He's been in two placements. He's just having problems."

[Tape 21, Side B]

Heumann: He was just kind of a sassy, independent guy who was not going to work well in kind of a controlled environment. Well, he came to the right place [chuckles]!

The Independent

Heumann: Then we had this publication called *The Independent*, and Vickie Lewis came on. *The Independent* was the hottest thing going. But I think it's the kind of time where you really wished that there would have been some people there who really could have just helped to hold onto it. As I've said over and over again, to me the money thing was always such a shame. It's just amazing the creativity that was within that group of people. *The Independent* was, like, amazing.

Nurse and OT on staff

Heumann: We had a nurse on staff, right?—who was not a nurse. It was interesting to see how you could have a nurse on the staff who really wasn't a nurse but could be there to give information to disabled people if they wanted it and could talk to people—personal assistants and other people. We had an OT on staff. But they were all kind of fringe people.

Brown: It amazed me that there was a nurse on staff. It seemed astonishing that they would have a medical person on staff.

Heumann: She wasn't a nurse. She never was dressed in whites. But people had real issues, you know? Decubiti ulcers and all kinds—and Edna Brean—she was so non-medical. But she was medical. I mean, she knew medicine. Like Alexander Enders, who was the OT, and [Judy Rogers], who was another OT. But, you know, that was where the degrees were good because they had experience, but they weren't there *because* of their degrees. They weren't there just <u>because</u> they were an OT.

Brown: They obviously weren't totally medical model or they wouldn't have been there.

Heumann: No, exactly.

Brown: I try to imagine an ILC now, having a nurse on staff.

Heumann: Actually, they do have them in the personal assistant service, but they're very different.

Brown: Exactly. That's what I mean. Just to think of it is sort of—euww!

Heumann: Weird, right.

Brown: But then, reading the in-house monthly [the CIL In-House Monthly], well, that's obviously not—

Heumann: Are you reading the in-house monthly?

Brown: I had a bunch of them, yes. I don't have them, but—

Heumann: Oh, I'd love to—

Brown: —I could certainly.

Heumann: That would be helpful also, to think about things. Yes, the Blind Services Program, the Deaf Services Program. Oh, when the computer training program—when it started—I was there when it first started, when IBM came. Scott and Neil were the ones who really got the program started. But I remember having the meeting with IBM, talking about what we wanted it to be. So we were the first computer technology program. It was all, like, great, great, great stuff.

Brown: I can imagine.

Heumann: Yes.

Brown: Is there anything else you want to say about being on the board, or should we move on to—

Heumann: I'm way beyond the board.

Brown: I know.

Appointed as Deputy Director of CIL

Brown: I think you mentioned a little bit when you were on the phone with Joan, but if you could just say a little bit more about it—how did you get the position of deputy director? Do you remember how that happened, when you found out that it was something you would be taking?

Heumann: Ed got asked to be the director of Rehab. He was sworn in, I believe, in September of '75. Then Phil was becoming the director.

Brown: Was Phil the director before that?

Heumann: I think so.

Brown: So that was a title that existed before. It wasn't made for you?

Heumann: I don't remember, I don't remember.

Brown: So Phil was made the director—

Heumann: Phil was made the director, and then they asked me if I would come back and be—I think it was called deputy director. I'm pretty sure. That's what my résumé said, right, yes. Not to worry—you know, I was like, I've got this job and it's paying money, and I need money, I have to pay my rent, and da-da-da-da. I wanted to get off SSI and IHSS. So, "Don't worry, be happy." I believed them. I mean, it was clear that if I didn't go back, I didn't have to go back because I had already completed what I needed to do for the university because they had made those changes. But it was also very clear that if I didn't go back, I was never going to go back, and I did want to go back.

Brown: If you didn't go back to Berkeley?

Heumann: Yes, if I didn't go back around that time, given the changes that were going on. I couldn't be assured of being able to be in any kind of reasonable position within the organization because I'd been away for so long. So it was kind of—you know, I got the feeling that people liked me, they respected my work, they wanted me to continue to be involved, and to come back and work with Phil.

Brown: Was there any talk of you being director?

Heumann: I wasn't there then. I don't know how it went on.

Brown: Was it a position that you wanted or thought you should have had?

Heumann: No, I never—no. Phil was always underplayed and always undersung and undervalued in a real way because I think he was such a very critical part of the vision and development of the organization. But he was more a street guy, you know? He definitely did not have a big ego. He was one of the few men I've ever, ever worked with who did not have a huge ego and was very—you know, he was a Vallejo guy.

Brown: What does that mean, a Vallejo guy?

Heumann: He wasn't a city guy. He was in a car crash, drinking. Then he wound up in a nursing home or a county facility and then eventually got out. He was there for a good number of years. He was always kind of this understated guy. Cared a lot about things, was great with people. People trusted him—people like Mary Lester and Lynn Kidder and Joan. They really liked him. He was a good person to work with.

Brown: So there wasn't an interview with the board or anything like that? It was sort of "Come be deputy director." "Oh, okay, I will."

Heumann: Pretty much. There might have been some interview, but it certainly doesn't stand out in my mind.

Brown: It wasn't a big deal.

Heumann: No. First of all, this was not like a heavily competed position because the truth is they weren't advertising a salary; they were just telling schmuko over here that they had money! So she's like Pollyanna in the most pink glasses. Sure, I believe you! I had heard

that there was some financial problems. A little bit of things I had heard about. I was hearing a little bit about it. But it really wasn't until I got back that I started hearing more about the financial problems and one of them being I didn't have a salary!

Brown: Did you feel that you had been deliberately misled?

Heumann: Oh, sure. I was very annoyed.

Brown: They were just doing this as a way to get you back?

Heumann: Well, I think it was a couple of things. I thought I was pretty stupid. How could I leave a job, lucrative as it wasn't? Why didn't I just stay another couple of months? How could you really be too angry at anybody else where in the end I did have free choice? No one came and packed up my bags and said—Rehab didn't say to me, "Your job is being taken away." None of that was happening. It would have ended at some point, but at that point, wasn't. What can I say?

Brown: So you thought it was a couple of things—partly that you maybe didn't make the best choice in going right away when you didn't need to, but—

Heumann: But that wasn't a big thing. I mean, I was glad to be there because I could just get in there and start—you know, the ACCD had started. I was involved in helping to set that up. We were doing the 504 work. IDEA was finished, as far as the statute was concerned. I pretty much had learned what I needed to learn. I could have stayed there and kept my job and moved up, but D.C. was more difficult for me because it was more the East Coast city, where you couldn't—there was no Metro at that point. There weren't curb cuts in many cases.

Brown: Right. It was just harder to get around.

Heumann: Personal assistant services was difficult, driving around was difficult, I didn't have as many friends here as I did either in New York or in California.

Brown: There wasn't much of a disability community here at that point, was there?

Heumann: Not much more than there is now [laughs]. There was less then, which was kind of scary.

Brown: Yes, that's terrifying.

Transition between being a board member and a staff member

Brown: What was it like for you transitioning from the role of board member to staff person?

Heumann: You really have to understand that these distinctions of "board" and "staff"—the organization was so small at that point. I mean, there was a distinction, but it certainly wasn't based on anybody earning a lot more money than anybody else did.

Brown: No. No, no, no. But—

Heumann: It wasn't those kind of delineations. It's very true that the board made certain decisions and gave certain directives to staff. But because the organization was relatively small, it just wasn't a big deal.

Brown: It doesn't sound like there was the tension between board and staff that came later.

Heumann: Right.

Brown: I think that's why I'm asking the question, is if that was going on earlier, I would imagine that would be a source of tension.

Heumann: Not really. No, not to me.

Brown: It must have been nice to be back in Berkeley, though?

Heumann: Yes, it was always this thing for me. It's like when I was back East, I was closer to my family, so I really liked that also. I could see my parents more often. My parents came down to see me. I could get up to New York more frequently. So that I really missed. There were things about the East Coast—you know, like now—that I really like better than the West Coast. You know, the West Coast—it's easier to get around, but it's also smaller. They don't have as much to do. The museums and things there, the theater on the East Coast. Those are all things that I liked a lot better than on the West Coast.

But I worked really hard. The first year I came back, I worked every day, seven days a week, and I worked in the office.

Brown: At CIL?

Heumann: Yes. I hardly took any time off. There was just so much to do.

Brown: I wanted to ask more about that, but we'll do that later.

Strengths brought to deputy director job

Brown: What strengths do you think you brought to the position of deputy director?

Heumann: Well, I had a whole level of skills that were different than what other people had there because now I had been in D.C. for a year and a half. So I think my skills that I had learned from doing work with ACCD and working in the Senate in particular—the order should be reversed: working in the Senate and—it was my Senate experience, it was working with a lot of the national disability rights organizations—which I had started to do when I was involved in DIA.

CIL wasn't connected like that. It was a local, West Coast organization that, as I had said earlier, wasn't even seen on the national scene until one of the demonstrations, and then it was two people kind of being there, and they made no—

Brown: Nary a blip.

Heumann: No, no, not a blip. I think I did help bring more of a national perspective because I talked a lot about CIL when I was back in the East, and then when I went back to the West, I continued to try to develop my contacts back on the East Coast. As Ed was working in California on getting other independent living centers started, when he was using the federal-state rehab money—and as the centers—

Networking to develop statewide coalition

Heumann: That was the other thing that was going on. There were these centers that were developing around the state, and so there was this networking that was going on of people that had known each other through the Disabled Students' Program or other things, some of whom I had known and some of whom I didn't—as that was starting. Then we were beginning to start to meet and work on developing the state coalition. My contacts there definitely helped on getting the federal hearings on independent living because it was people that I knew that I had convinced—

Brown: And those were when?

Heumann: Seventy-eight. So there were all these things that were happening—different programs developing, the litigation going on around the bus issue, the 504 demonstrations, the ILC hearings for the federal legislation, the work for the state legislation on independent living, getting the Tom Bates bill through on independent living.

White House Conference on Handicapped Individuals, 1977

Brown: What was that bill?

Heumann: I don't remember the number of it, but it was the first state law that provided funding for independent living centers—yes, with the formula and all that. The development of the coalitions. I was involved in all of that. The White House Conference on Handicapped Individuals I was very involved with.

Brown: Which one?

Heumann: In 1977.

Brown: That was in?

Heumann: Washington. Well, first every state had to have a state meeting, select its delegates to go to Washington; but I was part of the delegation that went to Washington.

So I was very—what did I offer? Again, I think I offered energy, I offered vision, I offered cross-disability, I offered youth through seniors—because we did start a senior program, this great senior program through the blind services. We had mobility instruction going on. We had so much stuff! It was just amazing. Never enough, but you could see all these things being—you know, you couldn't meet the needs of people at all, but you could do so much more.

Then, when the organization, like, went from two hundred to thirty-two, we couldn't do the same thing anymore. We also couldn't help people who had significant, really significant disabilities. It became a lot more difficult. We just didn't have the people to do the buddying and the networking and all these different things that were going on. There was the paid work and the friendship work and just so much stuff happening.

Work with state institution in Santa Rosa

Heumann: I remember with one of the projects that we were running at the state institution in Santa Rosa—Joanne Jauregui, Dale Dahl, some of the guys were doing this program with the deaf individuals at Sonoma State. I got a call from some social worker at the hospital because they were getting two people out—could I help them find an apartment—we're doing all this stuff. She said to me, "If anything happens to these people, this will be <u>your</u> responsibility." I said, "Oh, my God." [chuckles] It's like, okay, we're going to have this guy. This black, deaf guy—one of the guys that were getting out. I'm trying to remember his name. The [old?] guy.

The guy's going to go across the street, get killed, it's my fault. I said, "Yes, I understand." [chuckles].

They did great stuff with these two people. So much of what it was was attention, time. Time intensive, no doubt about that. Very time intensive. Being there and making sure you had good role models and the right people to be working with people. Certainly, skill was definitely a part of it. Some in-service training, and some people went back and got master's degrees, Ann Cupolo being one of them. We had a master's—Antioch had that program there. I mean, it's kind of amazing, you know. Think about it; we were doing it, in one way or another.

I was on staff until '81, I guess, and then I went and worked for the state, and then I got on the board. That's when there was—yes—I'm trying to think. Howie the Harp got me elected to the board. They overthrew the board. Yes, it was a membership organization—definitely was. It was Howie and a bunch of people—got most of the regressive people off the board. I got on the board, Margaret Jakobson I think got on the board, and that's when Michael Winter got the job—because the other board was looking at hiring a nondisabled person because they could run the finances better.

Brown: There you go. We don't have a lot of time left before the van comes. One brief thing I want to ask is if you could say what ACCD stands for.

Heumann: American Coalition of Citizens with Disabilities. I thought we discussed them, didn't we? We did discuss them, but I'll say it again. We never discussed them?

Brown: If we did, it wasn't in significant enough detail for me to remember it. I know what it is, and you know what it is, and I think people could look it up elsewhere. I just wanted them to have that acronym in case it wasn't anyplace else.

Heumann: Yes, American Coalition of Citizens with Disabilities.

Ed Roberts leaves at critical time

Brown: So you came fairly soon after Ed had left.

Heumann: Yes.

Brown: Did it feel to you like that was a pretty big deal? Or had folks pretty much settled down from Ed's leaving?

Heumann: See, Ed wasn't there that long. I mean, he was involved with the organization from the very beginning, but he was a director for a short period of time. He wasn't the director for the whole time that I was away. I don't even know if he was the director for a year. I don't know. I'd have to look it up. He had done good stuff, but of course there was also this money problem that had become more pronounced.

Brown: Did people feel that that was his fault or responsibility?

Heumann: Yes, definitely part of it, yes.

Brown: Did people feel that Phil would do better with the financial end of things?

Heumann: I don't know, because I wasn't there when that part of it—I wasn't—I don't know. I mean, I think that people felt—you know, Ed was definitely a dreamer, and he was definitely a creator, which was great about him. I think he kept feeling like something would happen. He didn't abandon CIL. He definitely worked with CIL and tried to get things going. He certainly helped make good contacts, the organization.

Duties as deputy director

Brown: So what were your responsibilities and duties as deputy director?

Heumann: At CIL?

Brown: Yes.

Heumann: Geez. Did legislative—as we got bigger, we got more people on to do more management, but I was over the legislative, I was over a number of programs. Employment reported to me. At one point we had a services director. Then—I really have to think about this for the next time. I had a lot of people who reported to me. Phil and I worked a lot together. I did development with Phil. [yawning] I did a lot of work with. I would love to see a little chart.

Brown: I'm looking at this staff list. We can actually stop for tonight because the van will be coming soon.

XIII. Management Roles At CIL; Dynamics between Judith Heumann, Phil Draper, and Ed Roberts

Reporting lines at CIL

[Interview 13: May 5, 1999] [Tape 22, Side A]

Brown: In the last interview, we covered quite a bit about your responsibilities and duties and a little bit of what you did at CIL, and I'd like to move into stuff about the people that were at CIL. What I'd like to start with is: who did you report to at CIL, in terms of your work, if anyone?

Heumann: Phil Draper.

Brown: Did he report to the board?

Heumann: Yes.

Brown: But you weren't directly responsible to the board?

Heumann: You know [chuckles], I reported to Phil. Phil and I reported to the board. I mean, we were still a growing and emerging organization. I reported to Phil, and then Phil and I would regularly report to the board, because we had different areas of responsibility.

Brown: Who reported to you?

Heumann: I don't really remember at this point. At one point we brought Michael Winter on, who came on as the services manager. Before that, Phil and I divided up the different programs. A number of the service programs reported to me. I'm trying to remember. I worked with the R&D Project, I worked with a number of the service programs, I did legislative work. Phil was over fund-raising and over—they must have a chart, an organizational chart. Do you have one?

Brown: Not exactly. It's got different sorts of departments.

Heumann: Let me see. When is this? This is later.

Brown: Do you want me to turn it off while you're looking?

Heumann: Accounting reported to Phil. Phil and I worked with advocacy. I think advocacy reported to me. The attendant referral [examining document]—the design, the machine shop, the wheelchair repair billing, the wheelchair repair—that all reported to Phil. Computer training program reported to Phil, to me. Disabled People's Legal Resource Center. Yes, here's Jim [James] Pechen. That's when that program was up and running. You don't know the date of this, do you?

Brown: I thought I was told that it was late '76, '77.

Heumann: That would be right. Yes, development, public relations reported to Phil. I think the independent living skills, job development—

Brown: Those all reported to you?

Heumann: Yes.

Brown: What about blind services?

Heumann: I think blind services reported to me because Jeff Moyer did blind services. The Vacaville Prison Project—hmm—is this transportation? Transportation reported to Phil. Yes, I think more of the direct services. Phil did more of the wheelchair repair, van modification, billing, accounting—those programs. Eventually, as we got bigger, we brought in a services manager. The services manager, I think, reported to me.

Brown: Do you have any memory of how that was decided to break it up that way?

Heumann: I think it was based on how we were doing our work. We both worked on development, but it reported to him, because I was doing more traveling than Phil was. I think it was based on our expertise and how it fell out.

Phil Draper's role at CIL

Brown: What was your role in the organization? I'm also going to ask you what was Phil's role.

Heumann: It's funny you ask these questions. I think Phil and I worked very closely together, organizational lines. We talked to each other a lot; we saw each other a lot; our offices were near each other. We did a lot of work together. We did development meetings together, we worked on the Friends together. Lynn Kidder reported to him. Joan isn't on this list, so she's gone already. Phil and I spent a lot of time talking with each other about needs and issues and things we felt needed to happen. We met with prospective funders together a lot. I would meet with some, he would meet with some; but we would also meet with people together.

— 325 —

Phil was the longtime figure in the community.

Brown: What?

Heumann: Phil was not a newcomer to the community. I was still a relative newcomer to the community. As you can just see from the travels and stuff, I did a lot of the external work, and Phil did a lot of the internal work. But the newsletter doesn't talk about other work that was going on, like with the other centers. We were also doing a lot of work as the centers were being developed, as Ed [Roberts] was getting those programs off the ground.

Brown: You were both working with the centers? Or primarily you, primarily Phil?

Heumann: I can't answer your questions, "primarily," because we both did different things with different people, and we did different aspects of it, but as the centers were developing and meetings were beginning, we met with them. We went to meetings. Phil knew a number of those people more than I did because he had been involved with them over the course of the years. Ed knew these people well.

Brown: So it wasn't that you were representing the organization externally and Phil only operated internally.

Heumann: No.

Brown: It was just that you did more of the traveling.

Heumann: I did more of the traveling. As far as going to Washington, giving presentations around the United States, that was really more of what I did, although Phil did some of that, but not that much.

Brown: Because he didn't enjoy it as much as you did, or that was just how the roles fell?

Heumann: People knew me. They didn't know Phil that much. I mean, Phil was known more locally; I was known nationally. I was getting to be known locally. I think Phil actually came to one of the meetings that we did in Albany. Phil did some traveling. Went to a meeting in Colorado [yawns] where there was an IL [independent living]. He did a number of those. Mary Lester is who we should call. Should we call Mary Lester? Mary Lester would know all this.

Brown: That's okay. Let's just—

Heumann: Mary Lester was Phil's secretary, and she did a lot of these—

Brown: She's already been interviewed.

Heumann: Oh, she has?

Brown: So a lot of the stuff did already get done.

Heumann: Oh, good.

— 326 —

Heumann and Draper as a team

Brown: You said that you and Phil talked a lot about needs and those kinds of things. Were they primarily—I'm sorry, it's another "primarily" question—but do you remember, did you talk a lot about CIL, or did you also universalize it to talk about people with disabilities? Was he one of the people you talked a lot about?

Heumann: They weren't really separable discussions. We talked about CIL, obviously, as far as management of day-to-day issues were concerned—finance issues, development issues, long-range issues, opportunities. We talked about that a lot. But in many cases it was also in the context of bigger issues because CIL was just evolving at that point, so things were very interconnected. So we did both.

Brown: Did you find that you often came back from your travels with new ideas for needs and things that could be done at CIL that were needed, or were you already fairly aware of the broad range of things that people needed?

Heumann: Oh, no, the traveling didn't make me more aware of things that were needed. I think the traveling could make me more aware of opportunities that were available to help us deal with things that were needed. But as a rule, no, I wouldn't say that—because we were doing more than almost anybody was at that point, so it's not that—I don't want to say that we weren't learning, but I think basically at that point we were creating and creating based on the needs that existed in our community but were very similar to issues that existed all across the United States.

You know, if we were having difficulty with the board, we would spend time strategizing for board meetings, making presentations for board meetings. We worked on developing things for the Friends. We talked about city council issues, county issues, personnel issues—yes.

Brown: So you feel that you were a good team?

Heumann: Yes, I liked Phil a lot. I respected him a lot. He was a very hard-working person. He was revered by many. Definitely, there were a good core of people who had a lot of respect for him. He was not a flamboyant person. He was a very understated guy. But his hard work, his commitment, his personal story, and his commitment to people was very important.

As far as the techie end of things—wheelchairs, vans—he used all the different technology. He didn't drive, but he had a lift on his van. In those days, they didn't have what they have now, an EZ-Lock, where you can put your wheelchair in and it locks your chair. Then the van was lowering a part of the floor, not the whole floor. God, I haven't seen that in a long time, just thinking about that.

They had a cut-out. Phil would sit his chair on it and lower it down.

Brown: Like a platform that would lower?

Heumann: Yes, the size of his wheelchair. It would lower down a couple of inches.

Brown: That was for more headroom? Or what was the purpose?

Heumann: For a tie-down.

Brown: That was how he was secured?

Heumann: Yes.

Brown: So was there something holding onto the wheels somehow?

Heumann: I don't think so.

Brown: Or it was just because you were sunk, you couldn't go over the lip.

Heumann: I don't think so. I don't believe so, because I sat in it, and I don't remember tie-downs. We didn't tie ourselves down a lot anyway, then.

Brown: Do you want to take a break?

Heumann: We haven't done anything. How can I take a break?

Brown: If you're not feeling well, we can take a break.

Heumann: Go ahead. It's not that it's going to get better.

Phil Draper unsung hero of CIL

Brown: Okay. You have said in the past to me that you think Phil was one of the unsung heroes at CIL. I was going to talk about that later, but it seems like it might fit in well here, if you want to talk about that a little bit.

Heumann: Yes. Oh, do you have any questions? Or just talk about it?

Brown: Yes, if you'd like to talk about it.

Heumann: Okay. People know his story. He was from Vallejo and I think was in a car crash and then was in a facility, like a nursing home, for a while, and then got out. Has anybody interviewed Sharon, his wife?

Brown: I don't know.

Heumann: That would be great because she'd at least have more information about that. But he didn't go to college. He was a self-made person in a lot of ways. I think he was a father figure for many. I think there were others that didn't necessarily respect him over periods of time.

Brown: Because?

Heumann: Because I think they felt the problems that existed at CIL he didn't handle well. But I think as a rule people really admired him and respected him and believed in him. He worked very hard. He was very committed. As I said, he was very personable—you know, for the Friends. He was very tall; he was, like, six-foot-five. He would, in his soft-spoken way, say many important things. He had a strong vision why CIL was important.

He was very different from Ed. Ed was much more out there. He was more articulate than Phil in a certain way, but Phil I would never want to say wasn't articulate. He was, very. I think Phil is a modest person. I think that would be the difference, I think, significantly between Ed and Phil, that Ed was out there, in your face, kind of in his own way flamboyant and quite expressive. Phil was not that.

Brown: I also don't think I would use the label "modest"—

Heumann: No, Ed wasn't modest.

Brown: —based on my list of Ed qualities.

Heumann: No. Phil definitely was not a tooter of his own horn, no. But, as I said, he would be somebody I would just like to go in and talk with and think with. I did that with Ed also. Phil and I spent more time together in those years than Ed and I because Ed wasn't there any longer, so I spent more time with Phil in the eighties than I did with Ed in the seventies.

I think Phil was respected by the city council; he was respected by the county. He had been there for years. He was a figure. Was married eventually. I think Sharon definitely, for a long time, resented the amount of time that I took from Phil for work because we'd talk on the phone at night, we'd work in the office. You know, there wasn't a real beginning and end to work.

Brown: Let's talk about that a bit more later. She resented it, you think?

Heumann: Yes. Yes, sometimes she wouldn't let me talk to him, but anyway, we mended all those fences.

Brown: Did you have a good relationship with her at the time, or did that actually cause a bit of friction at the time?

Heumann: Our relationship wasn't that good for a long time, but it is now. I haven't actually talked to her in a long time, but along the time of Phil's being sick and then when he passed away, I talked to Sharon a number of times. I think anything that was, is no more.

What else about Phil?

Draper's strengths and weaknesses

Brown: Well, I did want to ask about his strengths and weaknesses as a leader. I wanted to ask that about a number of people. Would you like to go to that now? I think you said a bit about his strengths.

Heumann: Yes. His weaknesses—he wasn't necessarily as assertive or demanding as some would have liked, I think.

Brown: Demanding of?

Heumann: People. God, see, this is the kind of thing where I'd like to sit around with a couple of people and talk about people's feelings. I know that it's twenty-three years since we started working together—really, more than that—and my overall impressions and remembrances of him were, as I've been saying, that he was in his own way a strong person and in his own way a very valuable person, who cared a lot about many things. Many people had a great deal of faith in him.

His weaknesses? I know my weaknesses. I hate talking about people's weaknesses.

Brown: I know.

Heumann: I don't like doing that.

Brown: Well, maybe you could think of another way to put it that wouldn't feel like that. I mean, no one's perfect. Every leader has issues that they're stronger on or those when they are more effective.

Heumann: I remember the first earthquake I experienced. I was in the office with Phil and somebody else. It wasn't a big earthquake, but I remember feeling as if there were two plates next to each other—one moving forward and back very quickly—and there was a little noise. I just looked at Phil, and I said, "Is that an earthquake?" He very calmly said, "Yes." It was, like, no big deal. I said, "I'm outta here." I opened the door. I flew outside of that building—which, of course, was probably the wrong thing to do. He laughed and laughed and laughed.

I remember there was this other incident where—I like hot food, and he really liked hot foods.

Brown: Spicy hot.

Heumann: Spicy hot. Someone had brought him—you know, people would bring him presents. I remember this person brought in a jar of homemade pickled jalapeños. I'd actually never had one. I said, "Oh, can I have one?" "Sure!" he says, "help yourself. So we open the jar. He couldn't open the jar. I took one, and put the whole thing in my mouth! I was dying! He was laughing. So funny!

We worked on things like—when I think about important projects outside of the specific—there was the hearings that we had in the back of the CIL building for the federal legislation on independent living centers. I did the primary organizing of the day of hearings. Jack Duncan came out, and George Miller came out, the congressman from Ohio who has since died came out. [added during editing: Bill Tanter—San Diego ILC; Brenda Primo, Orange County; Tom Bates, Assemblyman (Berkeley); Loni Hancock, Mayor, Berkeley. There should be a transcript of the hearing.] Phil testified as the director of CIL, and we had—Ed testified. We had Senator Rector testify. We had a parent and a child testify about how the Berkeley Center had helped their child get into an inclusive setting. We had, I think, city council and county elected representatives speak about the importance of the center and how it was making a difference in the lives of people.

Those were some of the—we were doing these combination[s] of local-direct services, local-state policy. Phil was also very involved, actually, in the IHSS work, very. He was very knowledgeable about those issues. He was also very involved in SSI-related issues. He worked with Ralph Abascal for some things.

I'm just totally incoherent. Does everybody else answer these questions very methodically?

Brown: Everyone else—everyone else just is perfect. No, everyone does it in a different way. It's fine.

Funding issues weigh on Draper

Heumann: It was very hard on Phil in the latter part of the eighties, when we were having more of the financial problems.

Brown: The latter part of the eighties?

Heumann: The seventies, sorry. Because he was trying so hard. We were both trying so hard.

Brown: Both trying so hard?

Heumann: The funding problems. He was always trying hard. We never got over the original problem. I mean, here we are in '76. I think Phil had been the director a couple of months—because Ed was the director prior to that—and I think the center expanded without the economic base to do so. It was kind of like a betting on the come, which, again, I don't think you could be critical of because you kind of kept thinking that you could catch up. But we didn't.

When I think about Phil, I think, really, about his skills in the technology area. He would spend a lot of time with the guys in the shop—on the van issues, on the wheelchair issues, the repair issues, the Medi-Cal billing issues. God, we had amazing Medi-Cal billing issues, and he would spend a lot of time on the Medi-Cal billing issues—working with the accounting people. He did a lot of that.

Brown: It sounds like he was a little more detail oriented and more sort of number—

Heumann: He was more numbers oriented. I wouldn't say he was more detail oriented. We were just different detail oriented. I was more detail oriented—not more—but I was detail oriented around more the social service type things, and definitely detail oriented around the legislative issues. We both had these overlap[ping]—

[Tape 22, Side B]

Heumann: Yes. I always liked Phil to meet people who were coming in from other areas because he was great to talk with people about how we were setting CIL up and explaining what we were doing.

Okay.

Brown: Do you want to move on to someone else?

Heumann: Yes.

Discussion of Ed Roberts' strengths and weaknesses

Brown: I'd like to hear your take on the same thing for Ed—his strengths and weaknesses as a leader. I know that he wasn't at CIL at the time that you were there, so feel free to talk about—

Heumann: I think Ed and I were on the board together. Ed was big picture and not that into the detail—not that he couldn't be, and not that he didn't have good ideas about it, but he was big picture, moving on. A strong model. Phil was a strong role model, but different. If you looked at Phil and Ed—not literally next to each other but if I think of the two of them, Ed is out there, rolling about, big dog kind of ever-present. Phil was out and about also, but just more understated. Ed was a networker. Ed knew people from lots of different groups—banks and other places. Phil did, too, but it was just, you know, like, their style that was so different.

When Ed became the state director of Rehab, that of course put him in a different position, which was very important because he then was—now, I think, the first or one of the first—he certainly was the first state director of Rehab with such a significant disability. There's no doubt about that. Who had such a progressive perspective and was so independent living oriented and had done so much work. I mean, Ed worked with Herb Leibowitz. Phil worked with Herb Leibowitz from the Rehab Services Administration. But Ed was kind of bigger out there. The national meeting that we had on independent living. Ed got involved in international issues.

You look at a Meyers-Briggs or one of those kinds of charts, I think Ed and Phil clearly jump out at you. I think I was somehow in the middle, when I think about the three of us.

Brown: In terms of?

Heumann: I was definitely more externally oriented than Phil, more global—not that—Phil was totally supportive and understanding of it, but he was more local. I paid more attention to detail than Ed did.

Boy, this headache is amazing.

Brown: For the record, the tape should indicate that that was a cross-eyed, tongue-lolling face.

Heumann: [chuckles] Ed was moving. He continually was moving; ergo, the more similarity to me on that. Just, you know, when you think about his appointment, he knew people who—Bob Gnaizda and others, Sid Wolinsky and others—who felt that he would be good in this position. He was clearly—his vision and his level of disability also made people believe that he could be a strong leader for an agency like Rehab, to be able to put the message forward that disabled people were able to work.

Strong leader, weak manager

Heumann: But I remember hearing that when he took the position in the state agency, that at one point they, the governor's office, wanted to put somebody in as his deputy who they considered to be a strong manager because they didn't consider Ed to be a strong manager, but a strong leader. Most strong leaders are not great managers. There's nothing wrong with that.

Ed made all types of people believe in themselves and believe that there were other possibilities. That was just in his presence, which was always very powerful to see. He knew a lot about a lot of things.

I think about Phil and Ed. They both knew a lot about sports. You know me, I don't know anything about sports. I think about conversations when they would talk about sports—games and things. Ed knew a lot about a lot of things. He had a broad area of interests. When he won the MacArthur Fellowship, it was because of his broad thinking, his visionary way of being—and equally importantly, the fact that he got others, nondisabled people in particular, to see the value of the movement.

Male-female dynamics between Heumann, Draper, and Roberts

Heumann: I think for myself—you know, one issue that always went on for me, both with Ed and Phil, was the male-female dynamic. Both at CIL and at WID, I was in a secondary position, and actually when we started WID—Ed, Joan and myself—we started out with the three of us being co-directors. Then there was a terrible fallout with the board, where the board decided that it wanted a more traditional structure and didn't want three people to head the organization and wanted a director. Ed was willing to sell Joan and me out really fast on that one. I was furious. Phil never would do that, never.

Brown: Would Phil have fought the board, do you think?

Heumann: Yes. Ed clearly will go down as the person that people know, more than Phil. In reality, it's not right to say that their contributions were equivalent because it's absolutely fair to say that because of who Ed was, his impact globally was definitely broader than Phil's. But Phil really was the backbone of CIL, through the good times and the bad times. He was the kid that stayed home and tended to business, and respected the other work and recognized its value and importance, and really knew that we were on this—how to explain it—it's just something that kept mushrooming. I mean, it was a very unique time.

On the one hand, a sociologist could come in and could look at what was going on and probably parallel it to other movements and other organizations, but for us, being in the middle of it, it was just like little explosions that kept happening and kept getting bigger. It was because, I think, we all did believe—as I've said before—that we finally had gotten into positions where we were the creators. So many of the things we were doing were right. I fervently believe that.

But between the three of us, none of us had the business skills that we needed or the personal wealth that we needed. We all had the ability to convince different groups of people of the value of what we were doing, which I think was very important. We overlapped in our audiences, and then we had certain audiences that I think were drawn to each one of us for different reasons. But Phil and I at CIL, Phil and I when Ed was at the state agency—Ed left CIL early, and then did go on to help—got the money, took the money to set up these other programs. That was very important, and it was Ed's idea to do this—I think it was Ed's idea—to do this national conference.

Brown: The one at the Claremont?

Heumann: Yes, the one at the Claremont.

[whispering] I can't believe this isn't going away—[back to normal volume] in reference to my headache.

Brown: Do you want to take a break for a minute?

Heumann: Okay.

[tape interruption]

Brown: I'd be interested in hearing more about the—

Heumann: Is that all you want me to say about Ed?

Brown: No, no, no. Go ahead. You get to decide.

Ed Roberts as historical figure

Heumann: I think that Ed, over the course of his life, impacted so many people in so many different communities, and because he was a good chess player, you know?—pulling people together from different walks of life. That was very important. He knew different people in the foundation world and people he'd gone to school with at Berkeley. It was very impressive to watch him operate. He was less constrained. I mean, when I think about Ed and I think about myself sometimes, in, like, my job there was a value of not caring. Caring about some of the stuff that I find that I worry about in the job almost hampers your ability to be as broad as I'd like to be. It's not that he didn't care about it. He just wasn't interested in it, so it was somebody else's job to do it. That was important—I mean, in the realm of everything.

I'm surprised on a certain level that not more people talk about him.

Brown: About Ed?

Heumann: Yes.

Brown: In what sense?

People believed in Roberts' message

Heumann: People talk about him, but maybe it was that his death was so sudden, or maybe it was that we haven't yet anchored down the historical figures. But I don't get a sense that a lot of people who are coming up now through the movement necessarily know Ed Roberts, know who he was. That's an issue for us to make sure that people know him and know Phil. That's the value, I think, of this work, is to really allow people to know who the leaders were at the national level and at their local levels. Ed was a very powerful figure. I mean, he had a very strong sense of himself. That was very positive because he did make people believe in him and his message.

Brown: And what he represented.

Heumann: And what he represented, his message, right. I would get more literal. He would just fling it out there. I would feel sometimes this responsibility to put it in order, a little bit more in order. Sometimes Joan and I would laugh. Ed would be out there, and I'd be behind him, kind of picking things up because he'd promise somebody the world and they'd believe him, and so I didn't need to go up to them and say, "Ed can't give you the world." But I felt this need to let people know that I'd work with them and follow up. He would, too—try to cast things in a more achievable format.

But I think what I see in this position and Ed in his position is when you're in these positions, they're important because of the message they give to people, and so for people to be able to see Ed Roberts as the state director of Rehab was a very powerful thing. Of course, he had all these issues within Rehab. Some of the people loved him; others couldn't stand him. He sometimes, in my view, would go a little bit beyond the pale in being critical of things when he had to work with people. I tended not to want to be so critical of people that I had to work with—critical but [chuckles]—

Brown: Maybe a little more diplomatically critical.

Heumann: That might be right. But at the end of the day, historically speaking, for the people who mattered, he touched a lot of people. For the people he wanted to touch, he touched a lot of people. So I think that was very important, yes. Yes, definitely, he left lasting impressions on people, yes. I think it was because of who he was in toto—his intellect, his command of language, and the level of his disability. The level of his disability did let him jump-start things because people were just overwhelmed by his physical presence.

More on weaknesses

Brown: Did you want to say anything about his less strong points as a leader?

Heumann: Oh, I think I have. You know, he wasn't always as loyal as you'd like him to be, but you could also pull him back [chuckles].

Brown: Sounds like a big dog.

Heumann: [chuckles]. He wasn't into detail in many ways. He'd kind of be in and out. You know, he'd give speeches and, you know me, I'd try to pay so much attention to who the audience is and what I have to say and na-na-na-na-na-na-na—forget it! [laughs] You know, he'd—

Brown: Wing it?

Heumann: Oh, yes, he did wing it a lot.

Brown: It sounded like what you were trying to imply was that he wouldn't necessarily—

Heumann: Well, he didn't.

Brown: —know who his audience was, so he would just give a speech.

Heumann: Well, people would often talk about how Ed gave the same speech over and over again, which is why I would always, "Oh, God, did I say the same thing?" because on a certain level, when you give so many speeches, like he was doing, you can only say the same thing so many different ways [chuckles], you know? When people want to hear your personal story. But I think sometimes some of the disabled people needed to hear something else.

But overall, I think, he was a fantastic person—very powerful leader. When I think of Phil and Ed—both powerful, but Ed definitely much more out there.

— 336 —

More on male-female dynamics and Heumann's lack of confidence

Brown: I'd like to hear a little bit more about the male-female dynamics that you talked about. You just gave the one example of when you were three co-directors and that Ed—

Heumann: I'm trying to remember. Some of this has been me, that I haven't been more assertive and because I am this, like, team-y person.

Brown: Team-y?

Heumann: You know, work together. I can work with co-directors and things of that nature. Phil and I at one point—we were more kind of co-directors than we weren't, although we weren't called that. That's when I think my title maybe changed to chief deputy director or something. There would be issues sometimes—

Oh, boy!

Brown: We're having a headache moment.

Heumann: Yes, I think I need to stop for a second.

Brown: Okay.

[tape interruption]

Heumann: It was during the seventies that I was also getting more involved in the women's movement. Disabled women were beginning to get together. I haven't yet looked at all of the newsletter, but there was an ongoing section in there—what was that about?

Brown: It's just talking about the Disabled Women's Coalition meetings.

Heumann: Yes. I remember we went away—BORP organized a weekend of all women, and mainly disabled women, that was, like, so powerful. It was great. Phil and Ed both had their disabilities when they were older. Ed was fourteen; Phil was older than that. But I had had mine when I was very young. I think also it's still an ongoing issue with me of being assertive enough. It's not that anyone would call me a non-assertive, non-demonstrative person, but when it comes down to things about myself, you know, that I wasn't very good at.

Brown: Can you give me an example?

Heumann: Well, I was I think lacking in confidence on certain levels. Can I do it really as well as "the guys"? Nothing so clear, but I just think that some of it—it's not that I had less training than they did. Nobody had any training. On a certain level I had done a lot more stuff. By the time I came to Berkeley, I had organized national demonstrations and done more cross-disability and other types of activities. But I don't know. Finding myself was a strong theme of what was going on in the seventies—eighties and nineties [chuckles]. (I haven't found myself yet.)

Other people you want me to talk about?

Brown: Well, I was going to have you go over this list, but I think it might be better to save that for next time, since we have so little time left. Did you feel that Ed and Phil were sort of extra-male, or it was just male-female stuff that would have happened with anyone, given where you were at in your own self-discovery.

Ed Roberts and extra-male

Heumann: I think extra-male. Ed could be extra-male. Phil could be a little bit, but not that much, really.

Brown: Was that just who Ed was? Was it a disability thing? What's your sense of that?

Heumann: No, that was just who Ed was.

Brown: Did it happen in your interactions with the two of them, and with other men?

Heumann: It still happens because sometimes I don't know how to enter—you know, to command. I mean, I still sometimes talk about how I need to learn how to box because I feel sometimes if I learned how to box, I could get in there and spar. I can't explain it very well, I guess. You know, letting people take things away from me, not demanding the same level of credit, not taking the same level of credit for things that—I try not to take credit for things that aren't mine. That's not always the case.

Brown: What do you mean "that's not always the case"?

Heumann: Ed sometimes would take credit for things that—we wouldn't share credit—he wouldn't share credit. But on other occasions, he definitely would.

Brown: So, for example, someone would say, "Oh, congratulations, Ed, on getting that project funded" and he wouldn't mention that you had actually been the one—

Heumann: [laughs]

Brown: —advocating for that funding.

Heumann: That's an example, yes. But I think from a historical perspective, he stands on his own four wheels—or six wheels, actually. Six wheels? Four wheels.

Brown: I only remember four.

Heumann: Four wheels, four wheels with extended feet.

— 338 —

Involvement in early women's movement

Brown: Well, maybe you could talk a little bit more about your involvement in the early women's movement. Does that seem doable before we end?

Heumann: Well, certainly, just through the work that I did at Disabled in Action, that was our way of beginning our disability women's movement. Then there were other women who were, like, really in the women's movement—people like Adrienne Asch and Michelle Fine—people like that. Even Barbara Waxman and Ann Finger and some of those women who I think really—I mean, I did do work with women's groups, but my first loyalty was typically on disability issues. I would go to panels, I would go to conferences, I would be asked to speak at meetings on the issue of integrating disabled women into the women's issues—but I would only spend just so much time on that.

I was growing through it. It was more an opportunity for me, at that point in my life, to be doing work for disabled women. I didn't feel connected enough to the nondisabled women because I didn't feel that they were particularly interested in my being connected to them. So I would go to meetings and I'd give presentations. I didn't feel like really a part. I mean, symbolically I was a part. It was like one of the "Eighty Women to Watch in the Eighties." That was nice.

Brown: Was that in *Ms.* magazine?

Heumann: *Ms*. That was positive, but not that—period. That was positive. It didn't, however, make me feel more connected to the women's movement. It allowed me to say, Okay, the women's movement is acknowledging the need to do something with disabled women, so that was symbolically important.

I worked with a woman named Elaine Zimmerman? Elaine—put it on pause for a second.

[tape interruption]

Heumann: Elaine was involved in setting up the Women's Economic Agenda Project. I got involved with her in the beginning of that.

Brown: She was a nondisabled woman?

Heumann: Yes. I would say, on some real level, Elaine was the first nondisabled woman that I was ever involved with in setting up a women's group so that disability was more a part of the development of the organization from the beginning. Actually, the woman who is now the director, Ethel in Oakland—it's now an organization with about twenty staff, and they have at least one disabled woman on staff. Ethel has a niece who's got a disability, so disability is a somewhat integrated aspect of their work. That's kind of nice—it's a racially diverse organization—to see that.

Brown: Did you ever do a consciousness-raising group?

Heumann: With women?

Brown: Yes. I just thought that was something that they did in the women's movement, was have groups where the idea was to get your consciousness raised about women's oppression, et cetera.

Heumann: No, I—

XIV. CIL Staff in the Formative Years

Reminiscences about staff at CIL

[Interview 14: May 20, 1999] [Tape 23, Side A]

Brown: We're starting with Judy looking over a staff list. She's finding names on the list that she'd like to talk about—either say what she remembers that person did at CIL or her relationship with that person or anything interesting or clever she'd like to say about any of these people on this list.

Bill McGregor, bookkeeper

Heumann: Bill McGregor was on the CIL staff before I got there. He was basically the guy in charge of the books. Very nice guy who I believe had a drinking problem which I think now is cleaned up. He also was very into comics. I don't think he had any real accounting experience. He was kind of like good with numbers. So when the organization was starting, I think he was one of the primary if not the primary person doing the books.

At one point, there was a problem—"at one point" [chuckles]—there was a problem with the books. I think it wasn't Bill's fault, in my mind; it was just that we hadn't brought on anybody who was adequately trained. I believe that Herb Leibowitz, who worked for the RSA regional office, was involved in helping us to get technical assistance from the RSA regional office on our accounting, and eventually we decided that, as the organization was getting bigger, we needed a CPA, and we hired this guy, Rafe Taylor.

Phil and Rafe worked very closely together. Phil was involved in hiring Rafe. Rafe basically came in over Bill. I think Kari Eels eventually took Rafe's place. Rafe worked in some challenging times. He was an African American guy.

Brown: Do you remember how they found him?

Heumann: Rafe?

Brown: Was there a search?

Heumann: Oh, yes, we went through a search process to get him.

Brown: He wasn't a friend of somebody's?

Heumann: No, no one knew him.

Brown: One of those outside hires.

Heumann: No one knew him.

Brown: Was he disabled?

Heumann: No.

Ayeesha Dylan worked at the front desk. I just ran into her last year. She's a teacher now, I think. She worked there for a good number of years, an Asian woman.

Phil Draper, myself, Joan Leon. Joan, I guess, started working for Ed and then Ed went to Sacramento, and Joan did development and grant—well, grant writing and development work. Obviously, she's a very close friend of mine. She worked there until—I'm not sure—all this is '76 October, so I guess she left in '77.

Bette McMuldren was my administrative assistant. She—I'm trying to remember. Did she have a rehab counseling degree before I hired her or after? I don't remember. She now works for CARF [Commission on Accreditation of Rehabilitation Facilities], which is the rehab accrediting agency out of Arizona. I actually recommended her for the job. At any rate, she worked at CIL for a number of years.

Brown: Did she work for you all the time she was there?

Heumann: I don't remember.

Brown: Did she work for you for a while?

Heumann: Oh, yes, yes. She did grant writing. You know, we all did a bunch of stuff. She worked mail, telephones, did some grant writing—this, that, the other thing—worked on projects.

Gary Rowan. But he was not disabled.

Mary Lester, assistant to Phil Draper

Heumann: Oh, Mary Lester. Mary Lester was Phil's assistant, and Mary Lester also was involved in development. Mary and Joan were very good friends. Well, Mary and Joan and Bette—we

— 343 —

just kind of, like, always were working together. So do I remember them? Vividly. Mary and Phil had a close relationship. I think Joan and Phil had a close relationship. Was Lynn Kidder here at this time, in development? I think so. [going through papers] What was it called? Yes, Lynn and Mary had been very good friends for years. Mary was going out with this guy Tom, who worked in the wheelchair shop. Oh, see: Mary Dudziak. Mary Dudziak was my assistant, so maybe Bette at that time—this is October '96.

Brown: Seventy-six.

Heumann: I'm sorry, '76. I really don't remember. Mary became my assistant. I think after Mary was Laura Rauscher. I'd have to call Bette and ask her. Should I do that?

Brown: [no audible response]

Heumann: But [long pause]. Mary and Phil, as I said, had a good relationship. I think a direct relationship, where they were very fond of each other. Mary had been involved with CIL for a good number of years and was very loyal to Phil. So if I don't want something to be said?

Brown: You can say it, and then when you go through to edit it—I mean, you can say it now, if you'd like. "I don't want the following to be released until however," but that's something that can be decided later on in the process.

Heumann: You wonder why it's important. Mary felt very loyal to Phil, and she felt that Phil didn't get his fair due, that he wasn't given the credit that he should have been given. I think she had feelings about Ed, and Ed's over-committing to things. Mary was always a very funky, down-home kind of gal. She always dressed very funky. She was very, very smart, and she was a little bit shy about being as smart as she was. She has a great brother, and I met her brother, obviously, through her—tall, big guy, gay guy, into theater. John or Jonathan. She has a great laugh, and she could be very funny.

She was very involved in the union stuff. At one point, when they were trying to get a union involved, I remember that she—I'm not sure if she was Phil's representative, but she was very loyal, very committed to the philosophy of the organization, and I think felt badly for how difficult this was for us but in particular Phil because he worked so hard for CIL.

I'm trying to remember when she left. When I left, she was still there. I can't remember, honestly. But I would say that Mary was definitely—she was also very good with numbers, budgets. She and Joan did a lot of the budget development. I think the way the development was going, Joan was doing more of the grant writing, but Mary also did grant writing. Mary also did work with the private foundations. She was very well respected in her position, as I think was Joan. They worked together.

[whispering to herself]

Bette McMuldren, Ms. Heumann's assistant

Brown: Are you concerned about the dates? I'm sure we can either get that from Bette's interview—

Heumann: Oh, is someone interviewing Bette? Who's doing Bette?

Brown: She's done.

Heumann: Oh, I want to talk to her. She was great. She was married to a guy at UC. He might have been getting his Ph.D. Then they moved to Arizona because he got a teaching position, and he left her. He went back for a conference once or twice, met somebody, left her.

Anyway, things that I remember about Bette: We had heard that there was end-of-year money from the DD [Developmentally Disabled] Council, I think it was. We, Bette and I—Bette taking the lead—orchestrated getting staff to write all these grant proposals, with the hope of being able to get funding. Bette was very involved in deaf issues. I mean, she was learning sign language. She was friends with Dale Dahl.

She had a nice house. I think they rented it. She was from Ohio. She was respected by a lot of people because when I had worked with her, we were over services—did a lot of work with services. I think she also wrote the CETA grant that got us the Disabled People's Legal Resource Center.

Is this true? Are these on her tape? Oh, then talk to me!

Brown: [chuckles]

Heumann: Don't sit there shaking your head! Tell me stuff that she said.

Brown: I'm nodding when you say something that I know for sure is accurate. So that nod is not a yes.

Heumann: I'm sure I'm not divulging anything inappropriate. Did she do work after working with me? What did she do?

Brown: I thought she moved more into—

Heumann: Development, yes.

Brown: —development and grant writing.

Heumann: That's right. She went into working with Joan and Mary.

Brown: That was my understanding.

Heumann: Yes, I think that's right, because she had done all of this work with me, and I don't think she was really that happy in the position. I don't know if she wasn't happy in the position, but I think she wanted to be doing more writing and she wanted to be doing more of this

other—it was difficult to be my assistant and do this other stuff, so that's I think when we brought Mary on.

Personal assistance at CIL, WID, and in federal government

Brown: I have sort of a side question—we can come back to the list—which was were your assistants generally your P.A.s [personal assistants]?

Heumann: Yes. They did my P.A. work.

Brown: You said Laura was your—did Laura do your P.A.?

Heumann: No, Laura didn't do my P.A.

Brown: So then how was it handled?

Heumann: I think I just asked people. You know, CIL was very loose, and I think it was understood that everybody helped out, so we didn't have necessarily a person. Lots of people would help, depending on who was around and what was going on.

Brown: So there wasn't like a staff attendant position or anything like that?

Heumann: No. I don't think we had that. But people helped—like Mary helped Phil with his leg bag, Joan helped Phil with his leg bag, Bette did—people just did. It was just kind of what you did. I don't ever really remember anybody saying there was something they wouldn't do.

Carol Fewell. Carol Fewell worked for me before Bette for a short period of time. Except for Laura, other people would help out. But, you know, Bobby would help, Karen Parker would help—it just depended who was there. Pam Mendelsohn. You know, Maureen Fitzgerald. Mary.

Brown: I think it's an interesting thing that it seems to have changed a little bit, but, in general in disability organizations—sure, if you need it, someone will help you, but it's sort of considered, "Oh, that's the P.A.'s job."

Heumann: Well, a lot of organizations don't have P.A.s. Personally, I think there's relatively few groups that do. I think what goes on as a rule is that either people do themselves, they may quietly ask other people to help—it's not necessarily formal—or they do without. But at CIL it was just kind of expected—except for things like the interpreters, where you needed to have a qualification. We didn't look at personal assistant services as a rule needing someone who has this kind of training and qualifications, so it was just expected that people helped out.

It was nice. It's uncomfortable for me in a lot of cases, where I feel like it's so formalized. Today, I was told that we're going to have the boat ride. Leslie's not going, and Obrelle is going. But then Andy told me that Obrelle didn't want to help me while she was there because she was bringing her boyfriend, and so Laura said that she'd help me. But, you know, having to be so prescriptive about it—who's going to do it?—and it's only a two-hour thing. It's like if I even have to go to the bathroom, it would be one time. It makes it feel very uncomfortable for me.

Brown: In what sense?

Heumann: No one would think, at CIL, of saying no, they didn't want to do something like that—as a rule. You just kind of did it. People were friends. It's not to say that people didn't have borders or boundaries, but they weren't so classified. It made me feel badly when I heard that.

Brown: That Obrelle didn't want to—

Heumann: Yes, but it had to be assigned to somebody else. It wasn't through me—it's like these discussions go on around me. As close as I can feel to people, when things like that happen it just totally puts me off. It kind of like—it's like I don't know why I'm surprised about it because it's not like it never happened before. I mean, I haven't spoken to her about it. It was Andy who told me about it and, who knows?—somebody could have said something to her. I have no idea. But nonetheless, it does make me feel like at the office I have to feel very careful about who I ask.

You know, like Bea who would have worked great at CIL.

Brown: This is Bea Mitchell, who works for Judy in the Department of Education as her special assistant.

Heumann: Which is probably irrelevant to what we're doing right now. But at any rate—

Brown: No, I think this is interesting information, and I wonder if part of it is—

Heumann: You didn't fit in, as a rule, if you felt uncomfortable with people. Not everybody did everything. Of course not. I think the bigger the organization got, the more impersonal it got. But the smaller the organization was, people hung out together, or at least there were groups of people.

I didn't really hang out with Mary or Lynn, for example. Phil, I think, would socialize with them, definitely. Kitty Cone socialized for sure with Lynn. Now, Lynn and Mary did a lot of stuff together, and Mary's boyfriend and Lynn's boyfriend worked in the shop together, so the four of them did a lot of stuff together. They'd known each other a long time. Tom and Earl. Tom was Mary's boyfriend; Earl was Lynn's boyfriend. Lynn died, but that's I'm sure on the tape from a million people.

So anyway, I'm trying to think—see, I think the reader position at CIL—there was at some point a reader position, but that was different from personal assistant because the personal assistant in the office for most of us was not something that took a lot of time, you know? Move something, pick something up, do this, that, help somebody go to the bathroom. When I traveled, sometimes I took—like, sometimes Bette would go, sometimes Mary would go, and sometimes I had other people going.

Brown: Where they only CIL employees who went with you?

Heumann: No, not necessarily. It could have been my attendant.

Brown: Your home attendant, if your home attendant went?

Heumann: What we did at CIL was as a rule we tried to get other people to pay. CIL didn't do most of paying for anybody on anything! We did everything we could to get other money. That's usually the way I did my traveling. Then we would charge for the attendant.

Yes, but even at WID, other people would help me go to the bathroom; it wasn't just Maribel. You'd help me go to the bathroom; Joan would help me go to the bathroom. Who else was there? It doesn't matter. Anyway, so I just think that was—when you were in an environment that wasn't so bureaucratized—

Brown: It wasn't someone's job.

Heumann: It was everyone's job.

Assistants are bottom of the heap in federal government

Brown: Right. It was just expected that everybody would do all these things, whereas in the environment we're in now, the attendant is sort of the absolute bottom of the heap.

Heumann: But I don't think it would matter whether the attendant was a twelve or a fourteen. I really don't. I don't think it's the position as much as the work.

Brown: The actual doing of it?

Heumann: Yes. I think people are much more body conscious.

Brown: On this coast?

Heumann: In the federal government. I can't speak about the coast.

Brown: I agree with that.

Heumann: So it's like there are people I ask, for whom it's not their job, but as a rule you have to kind of feel the energy. "Well, how do you think they will respond if I ask them. They can't say no to me because I am their boss." That's the other thing I always have to worry about, is I can't ask—but I could ask Diane and I could ask Veronica and Laura. I don't ask Sarah because she's got a bad back. But there just is a different dynamic. But actually, you know, the personal assistants are in the lower rung, but there are lower grades people have. There are sevens.

Brown: I'm just saying in terms of how I felt I was treated when I was there [working as Judy Heumann's personal assistant in the federal government]. I definitely felt that I was treated as a little chained monkey and that I was supposed to just sit there and be quiet.

— 348 —

Heumann: But I don't think it's as much for the PAS [personal assistant services]; it's whether there's respect or not respect for the grade level.

Brown: To me, it was definitely because I was your assistant and therefore I was nothing. I was just around to help you go to the bathroom.

Heumann: With all your computer skills and everything?!

Brown: This was just in general, how I felt people treated me when they came into the office. I was either a receptionist, so I didn't deserve any respect; or I was just a chained monkey that picked up Judy's pencils.

Heumann: That's not what I heard people say about you.

Brown: I'm not saying personally, not anybody that knew me, once they got to know me. I'm saying as a category, as an entity, as a symbol—

Heumann: Staying in the front office.

Brown: —I was not worthy of very much respect.

Heumann: Sure, it's the grade levels.

Brown: But I think if you were to add to that being a woman of color—which I'm not—I think that that could get pretty [strained? strange?]. It's also just wanting to be off duty sometimes.

Heumann: But you know, you weren't on duty. [check this part—editing unclear p. 639]

Brown: Right, but that's the whole difference about—

Heumann: You know [at CIL] you could go to somebody and say, "I need to go to the bathroom. Do you have time?" Somebody would say, "I really don't right now. Could you ask somebody else?" If there wasn't somebody else, you could come back and say, "No, there wasn't somebody else." But otherwise, it was like, okay—there could be times when someone needed a lot. [added during editing: At CIL there was an expectation that most people helped out—it was natural. I used a personal assistant to travel. My assistant, like Bette and Mary, helped me more than others, but Laura was a wheelchair user, she couldn't help me.]

Like, Hale had an assistant. Hale had an assistant whose responsibility was to work with Hale, because he needed a lot of help moving papers, making phone calls, doing interpreting, all of that. So he had somebody who was his assistant, who did provide him with more assistance, as a rule, although other people would help out, too. But it was because he actually had more needs than many others.

But then, as I said, the blind employees had readers, and the deaf employees had interpreters. So I think the PAS issue, itself, was treated somewhat differently. I think it just kind of naturally evolved. I didn't as a rule hear people complain about it. We didn't have any, like, issues of "We should really be hiring people to do personal assistant services"—not that I recall, at least.

Assistants at WID

Brown: This is jumping ahead, but do you remember that happening at WID? Because there was a staff attendant at WID. It was me. Did that come out of people saying, "I can't get anybody to help me" or "I need enough help to"—do you remember anything about how that happened?

Heumann: I'm trying to remember if the nature of the people who were—your job was to kind of assist numbers of different people, right?

Brown: Yes. I was called staff attendant.

Heumann: Right. And who did you assist?

Brown: You, if Maribel wasn't there, Hale if Nina wasn't there, the intern—what was his name?

Heumann: Dan.

Brown: Was Alana working there then?

Heumann: Not at that point. Alana came in later, as a summer—but that was another way for us to deal with it, I think, also. Maybe we were getting old and more sophisticated. People had more responsibility. We had more people who couldn't do it because they had back problems and various and sundry other things. We were doing personal assistant services research.

Brown: Was Julie Weissman there then?

Heumann: No.

Brown: I remember working with her. See, I think I was somebody that people would ask, even if it wasn't my job at all.

Heumann: Right. I think we wanted to make sure that people were assisted. But still, you know, there was a general assumption that everybody did some level of assistance. But then Ed did have his driver-attendant that was paid for.

[Tape 23, Side B]

Heumann: Any other questions?

Brown: Not on that.

More reminiscences about staff at CIL

Heumann: Jack Rowan. Jack Rowan was involved—okay, there's three names under Advocacy: Jack Rowan [Rachel Cranston?], Greg Sanders. I don't know if Rachel Cranston wasn't also doing personal assistant services with them. They were both quads. It might have been in some job description, personal assistant services or attendant services.

Greg Saunders, IHSS guru

Heumann: Greg Sanders was kind of like one of the big gurus in IHSS and Medicaid. He and Doug Martin were two of the best people in the country, and very competitive with each other. High levels of testosterone. Didn't work and play well together. Kept things close to the chest, trying to not let one center outpace another center. But the guy was brilliant.

Brown: This was about IHSS issues?

Heumann: His area of expertise was IHSS, personal assistant services, Medicaid. He was the numbers policy guru. Well, of course, then there's Hale, too. But that's what he really focused on. He helped people when they had Medicaid problems, IHSS problems. He helped me get my IHSS. He counseled me on how to talk to the IHSS workers when they came to the house. The purpose of my interview with the IHSS workers was not to tell them what I could do, but to tell them what I couldn't do, because if you told them what you could do, it was less likely that you were going to get the hours that you needed. Since the full hours that you needed didn't cover what you needed anyway, you really had to be careful [chuckles].

He—oh, God, I remember! I was living on Haste Street. It was before I was working at CIL, and I was applying for IHSS. A social worker came to the house, and I remember [chuckles]—oh, God—I didn't do anything inappropriate. I just exaggerated things. I remember at one point when she came in, I was in the bathroom and the bathroom could be seen, and I remember, like, lifting my hand with my mouth—

Brown: [laughs]

Heumann: But Greg was great. He would help people with their PASS plans. He had a PASS plan. He bought his house with his PASS plan. I think he's probably one of the only people In the United States who bought his house with a PASS plan. He was brilliant in his area. He was also pretty conservative in his thinking (whatever Berkeley conservatives were). He worked with Ralph Abascal. He would go to Sacramento a lot. He would work on the county issues a lot. He was, like, a real incredible resource. People relied on him very heavily. He kept things to the chest. He was not an E in the Meyers-Briggs. He was, I'm sure, a raving I.

Jack Rowan in advocacy

Heumann: Jack Rowan. I think Greg and Phil went back. Greg was a quad; Jack was a quad. Jack Rowan's brother was—let's see where he is. Was he on staff then? [looking at papers]

Jack Rowan worked in advocacy. He also did counseling. Jack at one point also, I think, got his degree from Antioch, and he eventually—I think he left staff. I think he might have gotten on the board. He was chair of the board at one point. Has he been interviewed?

Brown: [no audible response]

Heumann: He moved. I think he's in another part of the state. But a story about Jack. CIL, you know, got quite large. We had a lot of space. Then when [then-President Ronald] Reagan came in—it was after the strike—Reagan came in, we were losing money and dealing with our budgets and laying staff off. It was horrible. Jack said to me he really looked forward to the day when we had about thirty to thirty-two staff. I remember when he said this to me because it was in the building across the street. That's where my office was at that time, over by the Disability Law Resource Center.

I remember getting very angry and thinking that all the work that we had done to get the organization built up and all the great work that we were able to do—and feeling so angry because what he wanted was something that was small and manageable. I tried not to express my anger that much—yelling, which is what I wanted to do. I remember saying to Jack, "How could you say that? What's going to happen to all these people who have jobs? What's going to happen to all these people who depend on these people to help do things? Who's going to do this? Who's going to replace this? How could you feel good about this?"

But it was an issue of people feeling overwhelmed about what they could or couldn't do. So it was easier to get the organization to a manageable size than to either switch us, gain new skills, try to get more outside help. We had consultants on a regular basis at CIL coming in; regularly, we'd be working with different people who would come in and help us—looking at different ways of doing our fund-raising, looking at different ways of doing our management, looking at the general kinds of things that organizations have as they're growing—or even when they're smaller.

But Jack just—nice guy. When he was in advocacy, did good work. He got what he needed. I remember that story vividly.

Attendant referral. Okay—anyway, advocacy. Where was Hale listed in that? With Kitty. What the heck did we call that? [going through papers] Community affairs. Yes, there was community affairs.

Anyway, advocacy. Saw clients, did work with the county on the IHSS budget, did work in Sacramento, did work in D.C. Greg did go back, I think, a number of times to D.C. on issues and was, as I said, a real resource.

Lynn Kidder in billing and grant writing

Heumann: Rachel Cranston I don't know. I'm going back up earlier. I could see Lynn Kidder's name, under administration. She was in administration; then I think she was in development. Lynn was a very good writer. Lynn was—as I said before, she and Phil and Sharon—I think Mary and Lynn were in Phil's wedding party. I think that's true.

They had a great party. I remember that now. They had the wedding, and then they had the party in the basement of a church, I think. There was a lot of dancing. We did a lot of dancing. I mean, it was a very open time. We danced at Phil's wedding, and we had some CIL parties, like Halloween parties. Before the back of the building was renovated, we would have great parties in the back. Yes, the back of that building—boy, a huuuge, cavernous garage. We bought the building; then we were able to renovate it.

But when we had the hearings for—did we discuss the hearings?

Brown: The hearings on 504? Is that what you mean?

Heumann: No. The hearings on independent living, which were the hearings for the legislation that got the first federal money on independent living.

Brown: No.

Heumann: All right. Let me go through this here. Anyway, Lynn. I think I've already said she at one point was doing—she did development throughout her time there. She also worked in billing. Lynn at one point worked in wheelchair billing; yes, I'm sure of that. People did lots of different things. I think as we got into structuring the organization more, we tried to not have people being in so many different positions. But was there a separate billing office? Wheelchair repair, billing. At this point, she wasn't doing billing, but I know she did billing at some point. She did development, she did press releases, she did union stuff, she did—as I said, billing, she did ordering for wheelchair parts—yes, here she is: development of public relations. Then she's up there.

Brown: People are listed many times.

Heumann: [chuckles] Okay. What could you say about Lynn? She was very involved, I think, in helping with the 504 demonstrations. She worked with Kitty, I think, a lot on that. Did press work. Well, Dorothy Dillon, I think, did a lot of the press work. I think Lynn did some press work on that, too. I'm pretty sure of that.

Jan Balter, personal friend

Heumann: Jan Balter. Well, Jan Balter was a friend of mine from New York. She's on the list on attendant referral. Jan Balter was also good friends with Nancy D'Angelo. Nancy D'Angelo and I, as I told you, came out together.

Brown: You lived with her then?

Heumann: Right. Then Jan came out. Jan and I eventually lived together, when I moved to—was it Haste?—near Shattuck.

Jan Balter shared a place with me after I came back from D.C. I don't know if Jan and Nancy lived together for a while, and then Nancy was living with Tom. Jan was an artist, a sculptor. I think her medium was sculpting. She was beautiful—beautiful woman. She had asphyxia, I think, something like that. She had a sister who I think eventually moved out to California. She began getting involved with drugs. I think I told you this, right?

Brown: Jan or Nancy?

Heumann: Both.

Brown: You told me about Nancy.

Heumann: People would make comments about Jan on the street. Men would always be looking at her and whistling at her. It was unusual because most disabled people, that didn't happen. I don't know if it happened before she came to Berkeley, but she—she I think was friends with Phil Chavez.

Nancy and she were friends, and Nancy went out with Phil for a while. She [Jan] had a lot of boyfriends. Then her drug problems began to get worse. I don't remember. I feel badly about not remembering years that people died. But she wasn't living with me anymore. She moved out. We lost touch over time—not completely, but we weren't as close. She went to Europe with me.

Brown: I think you did talk about that.

Heumann: Right. We had a great time in Europe. She was involved in New York with DIA, and she—oh, God—the stories. I don't like feeling badly about talking badly about someone who died. I remember I was seeing Ralf Hotchkiss. We were in Washington. They started sleeping together, and I found out about it. I remember thinking—I was really furious.

Brown: At both of them?

Heumann: Both of them, but I'm sure I was more angry at her.

Brown: Why?

Heumann: Because she was my girlfriend, and I guess you expect a certain loyalty from your girlfriend. I think deep inside about guys—what can you say about them? But that was terrible. But then, you know, I moved on. We were okay again. She came out to California, but—she could be very funny. Nancy could be very funny. They were both smart.

But I think in many cases—you know, there were some people at CIL who just really—it's not that everybody didn't dabble in drugs. Susan O'Hara probably never did. [laughs] But outside of that, I don't really know anybody who didn't do something. But yes, definitely Mary—yes, everybody was into smoking dope. I was probably one of the few people who didn't smoke a little dope because it plagued on my morals. I think probably the biggest reason was I was afraid of losing control. This is no big surprise. But everybody else—not everybody, but lots of people liked kind of just losing. For me, I didn't like to be out of control.

But Jan—I don't know if she worked full time. I'm not sure if she worked full time. But she worked in personal assistant services.

Phil Chavez. Phil was in the first grouping of people that I got to know when I went to CIL. He and Nancy were lovers for a while, so he would spend time at my house. He would sleep overnight there. Fran, who was our personal assistant—maybe his attendant would come, too. They'd get positioned in bed, and that was always kind of funny.

Phil Chavez, peer counselor

Heumann: Phil was the one who turned me on to drinking warm water. I remember being at his house with the long straw and the warm water. Phil was involved with attendant referral. Then he got involved with the independent living skills. He was a peer counselor. I think he's still at CIL, actually. Or he was for a long time. His wife died. I'm not sure. But Phil—yes, Phil was one of the originals—like Greg and all that group.

I think he went to Berkeley. When we had foreign visitors, they would stay at his house. I think Uwe Frehser stayed at his house. I'm pretty sure Uwe Frehser stayed [there]—U-w-e, right? F-r-e-h-s-e-r.

So Phil had lots of responsibility over the history of the organization, and was a very respected person. I think the work that he did in attendant referral—interviewing and training disabled individuals—because he was a quad, he was very good.

Brown: Did CIL train the attendants?

Heumann: No.

Brown: Where did they come from?

Heumann: I believe we advertised in different ways—put notices out, advertised in papers, word of mouth.

Brown: Did you find attendants—

Heumann: We interviewed attendants—

Brown: But they didn't train them.

Heumann: They didn't train them, no. Did I find attendants through attendant referral? I did find some. I used the lists. But the other thing that would go on with attendants is you would find them from people. Someone wanted more hours or less hours or whatever. I don't know if we found Fran through attendant referral. Fran was one of my first—if not my first personal assistant. She was very nice and very good. Fran traveled with me sometimes. Did she get married to Jesse?

But anyway, attendant referral was always busy, always had a need for personal assistants because there was such a huge demand for it. We didn't do training because we didn't want to get in that position of training the attendants, but we did work with disabled people on helping them. Of course, we'd answer questions for attendants. God, you know, I don't know if we put the Attendant Manuals together.

Kitty Cone: thinker and strategist

Heumann: Kitty Cone. What can you say about Kitty Cone? Kitty Cone was and is one of my best friends. She's brilliant. She was very political. She worked in attendant referral, and at another point in time she worked in—what did we call it?—

Brown: Community affairs?

Heumann: Community affairs, right? She was the key organizer for the 504 demonstration, in the beginning. She was, like, one of our key people who worked on the committee. She was the key person on all of the work that was going on in transportation, both locally and nationally. She is a keen thinker and a great networker and a great spokesperson and a great orator. So Kitty got us involved in lots of things—everything from Gay Day to [chuckles]. But she wouldn't get involved in politics.

Brown: What do you mean?

Heumann: Well, she was a Trotskyite, and so she didn't believe in the traditional party politic. As we would get involved in campaigns or more bourgie [bourgeois] things, she would not get involved in any of that. What do I say about Kitty? It's my perceptions of Kitty, right?

Brown: Absolutely.

Heumann: Kitty—you know, like so many of the people in this group—was very respected and a big part of the family because she was such a keen thinker and such a hard worker and a great strategist. She was involved in working with legal aid on the litigation that we were involved with. She was great friends with Ralph Abascal. She helped organize demonstrations in Sacramento or wherever it was—organizing the vans and the drivers and the people. She was just a born little organizer. Not little. Born organizer.

She had great union contacts and religious contacts, and understood the importance of networking. It was easy for her to network with a very broad group or array of groups because of her background. She probably, more than anybody at CIL, had nondisability-oriented political training that she then applied—and through this she did have training because of the work she had done with the Socialist Workers Party.

I remember she took—how old is Jorge now?

Brown: Fifteen? I'm not sure.

Heumann: Sixteen or seventeen. Anyway, she was just this great part of the team on the 504 celebration, again. Kitty was with Alma [Noriega] in the beginning. That was the lover she was with when I knew her. Alma had a daughter, and Kitty lived in Berkeley, and she had a great house in Berkeley. I used to go over there. She had great parties, great dancing parties. I think at that point Kitty was not on the wagon, so the parties would be good music and whatever else going on. I just relied on her so very much.

[Tape 24, Side A]

Heumann: Kitty liked to dance. We would go to the White Horse, which is a bar everybody knows. She would do stuff at La Peña. She was so respected by such a wide—is so respected by such a wide group of people. I think she was the one that got us involved with the Black Panthers. Either she got them to come in or they came in, but I think she was involved with Brad.

Because she comes from the upper crust, it was [chuckles] always funny. Here, you really have this upper-crust woman, more than anybody else at CIL—she definitely was the upper-est of the uppers. Then you could be in Washington [chuckles] at a—she's very strong on the one hand, and then she can just be—well, stories about Kitty. God, I have to think about this. There's millions of them.

But one that strikes me at the moment is when we went to Washington on the 504 demonstrations, and we were in this, like, U-Haul van. We were having the rally, the demonstration outside of [Health, Education and Welfare Secretary Joseph] Califano's house, and she couldn't get out of the van because her relative lived on the block [chuckles]. You know, if a relative saw her, it was going to mean "Dah-dah-DAH"! I just remember thinking, "This is so funny."

Yes, great strategist. Worked on the ADAPT demonstrations. She did work with Cecil Williams.

Brown: I think it's fine where you're going. I mean, I think a lot more stuff will come out, certainly with Kitty, when we get to 504.

Corbett O'Toole in attendant referral

Heumann: Okay. Corbett [O'Toole]. Corbett worked in attendant referral. I don't remember how much time, but Corbett was involved with—there was a disability women's organization that Corbett was, I think, involved in having set up. She eventually went to the Computer Technology Program, and she worked as a programmer. I want to say that was probably more in the eighties, but I don't remember how long she worked at CIL. Did she work in the Kids Project? I think she worked on the Kids Project, right?

Brown: I don't remember.

Heumann: I would say that Corbett wasn't really a part of the inner group, whatever the—well [when] I think about it, I think of Phil and Mary and Lynn and Joan and myself and Betty and Hale and Eric Dibner and Ed earlier, and John Hessler. Corbett wasn't part of that group.

Brown: By that you mean the people that were making decisions, or just the people that were sort of in higher positions?

Heumann: No, I don't even—

Brown: What do you think that means?

Heumann: I think people who'd been involved with setting up DSP and CIL. It wasn't necessarily the position—because Hale and Eric—they weren't in, quote-unquote, "high-level positions." Nor was Kitty. They were advocates. No, but these were people who had been involved for a longer period of time. Tended to socialize together. People who had history together. Some of them were imagined positions, but, as I said, Phil Chavez—there were lots of people that just—Jerry Wolf—who just had been around for a long time.

Wally Wheeler, attendant referral

Heumann: Wally Wheeler. Wally was definitely one of those guys that was involved for a long time. What was his roommate's name? Bob. Wally and Bob. I went out with Bob for a short period of time. Yep, yep. A number of those guys I went out with—Larry Biscamp, John Hessler, Bob. Little flings. Wally was kind of a mainstay. Wally and Nancy D'Angelo went out for a while. Now, Wally also could do his share of drugs. I think Wally actually lived with John, the guy who worked at CIL who eventually got arrested for dealing? You remember John, the guy with AIDS.

Brown: Oh, McLaughlin.

Heumann: McLaughlin. There was a heavy drug culture, really. Disproportionate to anything I ever was involved with, before or after. I think, really, some people could do it socially and casually, and it was more difficult for others. Wally—Wally was on the social side of things. It didn't unduly drag him down. I think he still lives in Berkeley. He worked in attendant referral, but he was definitely kind of a mainstay person. He also had parties. We went to parties at Wally's house.

Phil Chavez lived in the same building as Mary Ann Hiserman. Mary Ann Hiserman also worked at CIL. I'm not sure if she's on the list here.

Wally was a funny guy. He could be a serious guy. Yes, he and Nancy. I think he and Jan Balter were friends, too. He was friends with Andy Cayting—Wally. I think he hung out with the people in wheelchair repair. He and Greg probably were friends, but a story about Wally:

I remember at one point he had said—I think this was after I was out of CIL; it was in the eighties; he did not hang out there any more either, any more at that point. He was friends with Phil. But anyway, he had made some kind of a statement about how he could streak down the street, and nothing would happen, and he went out one night, late at night, without clothing on, his leg bag. He went down one of the major streets, and cars did go by, and nobody said or did anything. I remember that.

He had parties also. Lots of people had parties. There were definitely parties. Booze, dope, dancing, food. Nancy and Jan got me to go out and do more of these things. I would go with them.

Megan Kirshbaum, intake and peer counselor

Heumann: Megan Kirshbaum. Well, Megan, of course—in the beginning, we didn't have intake counselors. I think the intake counselors really were a part of the federal grant that we had, where we were working with a certain population of individuals doing—was it the R&D Project? I think the intake counselors were an outgrowth—just seeing the number of intake counselors, we had one, two, three, four, five, six, seven—this was in late '76—you could tell that we were already beginning to pick up money, just by the numbers of people that we had working for us.

Megan worked in intake. I'm trying to remember if she was the coordinator for intake. But she—or was it Ann? At any rate, she also eventually did more counseling work. She and Lennis Jones did peer counseling. When we moved into having more formal peer counseling, Megan was very involved in helping set that up. Her husband was one of the people who set up the Antioch program. Hal Kirshbam—I want to say he was the director.

She did some very good work because she was with the organization for a good number of years. When I think about Megan—because now she's head of Through the Looking Glass—I think about somebody who was the creative individual who really was committed to development of the organization. Really helped us put some structures in place. As the organization was getting bigger, we were serving individuals who had greater needs, and we were working with people in a whole array—and as we did the public policy work—city, county, state and federal issues—we were also doing a lot of direct services, the goal of direct services being to work with individuals in helping them to determine what their goals were in their life and to help them resolve problems that they were having.

So the intake counseling in the beginning was very important. It was a way of our getting information on people, and also helping them not fall through the cracks. As the organization did get larger—I can't believe this is '76, but it is. As the organization was getting bigger and the needs of individuals were getting more involved and they needed or wanted multiple services, it was important to have an understanding of who the person was, where they came from—being able to make sure also that things were being coordinated.

Megan played big roles in all that. I think Megan also eventually moved out of intake counseling, as I said, to the peer counseling program. We had numbers of types of models, and she was the wife of a guy who had a disability, so that was also a role that she played. If couples came in, she could be involved in couples counseling.

I'm trying to think if she got one of her degrees through Antioch. Lennis Jones did get, I believe, his degree through Antioch. Ann Cupolo, who's on this list as Ann Pagano.

Brown: Was it another name, or it was just wrong?

Heumann: No, she was married.

Brown: Oh, Cupolo got married.

Heumann: I actually think Cupolo might be her maiden name, but Pagano was a married name, and then she was married to Steve, whose name wasn't Cupolo, and now she's married to Sam, who's Jewish.

Lennis Jones, counselor with Zona Roberts

Heumann: But Lennis—Lennis, more professorial. Lennis, the tall quad in the wheelchair. I think of Lennis as kind of an elegant kind of guy, serious. Lennis you wouldn't think of as the comedian of the group, although I think he did have a dry sense of humor. I think that would be fair to say about him. But on the serious end of life.

I have this vision—some piece of equipment that he had on his finger that he would drink with. He might have had water in the back, in a straw on his finger—or something. I think he had water on the chair. Old age.

He did go through Antioch. He did go on also to move out of intake and go into more formal peer counseling, and eventually I think he and Ed's mom, Zona Roberts, did maybe some joint counseling work together, outside of CIL—like couples—team counseling.

Did I talk at all about when I lived at Ed's house?

Brown: When you came back from D.C.?

Heumann: Right.

Brown: I think briefly you talked about it.

Heumann: Yes. But, as a I said, that's the reason I thought about Ed's house was because of Zona and Lennis's relationship. Zona—I don't know if she's here, but Zona worked in the counseling program at CIL for a while, and Lennis and she did some work there, too, I think.

Ann Cupolo Pagano, services coordinator

Heumann: Okay, Ann Cupolo Pagano. Ann came from New York. I knew Ann in New York, not that well but I knew Ann. I knew her husband better than I knew her. Ann has played a lot of roles at CIL—from intake counselor, to going to the Antioch program, she was service coordinator at the time—but she's always been in the services area. She never was in the grant writing or development. Obviously, she did management, which was after I left. She was head of services.

Ann is one of my best friends. God, stories about Ann! Ann worked with Nancy Rosenblum. Nancy Rosenblum was this friend of mine from New York who I went to elementary school with, who had cerebral palsy. I think I did talk about Nancy. She's the one who died. Maybe not. Anyway, she came out to visit, and I was, like, really cautioning her. She had more needs than most of the people at that point who were involved with CIL because not only did she have cerebral palsy but she wasn't able—I shouldn't say she wasn't able. She did not have, nor were they ever able to put together a system where she could push herself.

You know, that's a lie. That's wrong. We did eventually get her a chair that she did with her chin. But she never could really do it completely independently. At any rate, I didn't want to paint—she came out visiting with a friend—I didn't want to paint an easy picture because although we had a lot going on here, it wasn't that easy. "Here"—California. It wasn't that easy. Easier than in many other places, but you still had to have a good set of skills to be able to interview personal assistants and keep it coordinated and scheduled and deal with the paying and keeping your house in order.

Nancy was really not the first but one of the first people that moved us into working with a different group of people because many of the people we had worked with in the beginning—although there was the R&D Project and that did work with a different population—but as a rule, the people that we had been working with and for were people like ourselves.

Ann was Nancy's counselor. Ann would really help to make sure that she had a place to live, that she was getting the personal assistance she needed. We were trying to get her the different services that she needed. Ann worked with individuals who had more significant needs than she did. I think she also is very responsible and really wanted to make sure that people weren't falling through the cracks.

Independent living skills program

Heumann: There was this whole—everything that was going on was really to do what we could—a lot on the request of what the disabled person wanted. It was an empowerment issue—helping people to look at what they wanted to do, where they wanted to go. A lot of it was using our own personal experience. For the intake counselors and then peer counselors, it moved beyond that. I think what happened was that the Antioch program allowed

disabled people to go into a credentialed program that looked at health and psychological issues through a disability peer approach.

I think CIL allowed people to move forward getting credentials in an area that they were interested in, so they could learn on the job, and the organization also was responding because we eventually hired under consultants—the psychi—I want to say it was a psychiatrist. He might have just been a licensed psychologist. But he was disabled, and he would come in, and he would work with the counselors—Ann being one of them—to make sure that people were getting training that they would actually—go over, talking about people that they were working with in a confidential way, to be able to answer questions, get suggestions about how to help people. I don't want to say help people. I don't like those words. But basically to be of assistance to people who were coming and wanting to learn how to find themselves.

I want to say something about the independent living skills program that we eventually set up, which Phil was involved with. I don't know when Adina Frieden got involved. But the Independent Living Skills Program—it was Joanne Juaregui and Dale Dahl and a few other people. They worked on the independent living skills area for deaf individuals. They were working with—well, Joanne was head of deaf services. Deaf services did the more traditional work—helping people find attendants, making sure that deaf individuals who came into CIL were able to benefit from the whole organization.

We should talk about deaf services.

Brown: I've got a whole bunch of questions.

Heumann: Okay. But I also want to talk about independent living skills. We'll just do it another time because you only want me to talk about people, but that was a very important program. Do you want me to talk about that now? We could stop after that? Or go through people?

Brown: Why don't you finish with people.

Heumann: Carol Quast, to the best of my recollection, was a nurse who got multiple sclerosis. She was one of the intake counselors, peer counselors. She also—oh, God—she, when I was at WID, agreed to have, for a good number of weeks, a woman from Norway. You'll have to come back and ask me her name; I can't remember it at the moment. She owned a house. When she and her dad from Norway came, she was on a fellowship. Normally, we would go and check people's houses out before we had people—or we knew them. I think that's more important. Phil Chavez had a number of foreigners who stayed at his place. It was a way for him to make money. He'd rent the room out. I think he stopped doing it when he got married.

I lost my train of thought.

Brown: Carol—

Heumann: Sorry. She agreed to have the people stay in her place. I remember they told me at one point that the place was very, very dirty and that they had found a dead rat—oh, it was terrible! It was awful because it made me realize that even if you thought you knew somebody, you needed to check things out! We never hung out in her house. But, you

know, you saw Carol—she was a responsible person; she was respected. I didn't know Carol that well. She was a part of this group. But she was around for a long time. This was in the eighties, actually, when she was having people stay at her place.

XV. CIL, Through Role Models and Action, Empowers People with Disabilities

Common vision and needs

[Interview 15: May 24, 1999] [Tape 25, Side A]

Brown: Judy, in the last interview, we were talking a lot about the different staff members that were at CIL, and I'm hoping that we can get back to that and keep going through that list, and you say what you remember of those people, but at this point we're going to move on. I'd like to hear your answer to the question, Why do you think that those particular people were at CIL?

Heumann: The particular ones that I've spoken about?

Brown: All of them.

Heumann: Oh, anybody working there. Well, speaking for myself, I think that I reflected why numbers of people were there. It was—I described CIL in the beginning as like a candy store, because we were establishing the ground rules, and many of us who were working there were there because the organization was helpful to us in a lot of different ways. Speaking for myself, when I first came there, when I first came to Berkeley actually, I got most of my assistance from PDSP. But I got my assistance for my IHSS from CIL.

But we had a vision, we had an opportunity to come together and talk about what we felt was wrong in the world for disabled individuals and what we felt would work. We had some receptivity from funding sources. We had a growing interest on the part of disabled individuals who recognized the power of coming together to be a political group, although we didn't necessarily define ourselves as a political group, I mean not everyone thought, oh, this is a political group. But I think a lot of people did, but we gained support, we had opportunities to create programs that we believed would be beneficial, either to ourselves or to a larger constituency.

The working environment was reasonable. Some people would complain about the space and things, but it basically was, we were really able to make differences in so many ways

— 364 —

in the lives of ourselves and other disabled individuals, because we were a powerful group. For example, I had a social worker tell me one day that if you went down to apply for IHSS, for example, and they knew that you were from CIL, they always approved you, because they knew that if they didn't approve you, it would be appealed. Now, that was a very interesting statement, because it basically meant—here we were feeling like we didn't have a lot of staff who could really help people appeal, but we had done enough appeals that they had lost, that basically the word was out that it wasn't worth the attempt now.

She did also tell me that elderly people who didn't have representation were more likely to be turned down for services because they weren't going to appeal it. But nonetheless, the point in all that was to say that if you had competent people who—obviously competent meant they knew the system—who were going to be able to be there to advocate or it was presumed that they would advocate, it helped. So I think that was one of the issues.

I think most of us liked each other. We liked to be together, both at work and socially. We had a belief, many of us, that we could make a difference, that we could—that there were logical problems that were there. People would listen to us, we could resolve many of them. The truth is, we did. It was fascinating to see CIL grow as an organization and sad to see it go down when it did.

Cross-disability, cross-age focus to services

Heumann: But nonetheless, to me, as the organization grew, if you could put aside the financial issues that were going on and really look at the substance of the work, it was quite phenomenal. The wheelchair work that was being done, the way it was being financed, the design work that was being done was incredible. The van modification work that was being done. The peer support, the various types of peer support that were being worked on. The peer support for children and parents. The substance abuse program. The Disability Law Research Center. That struggle in and of itself, just getting the law center, the legal resource center set up.

Then the parent project, where there had been disagreements between some of the disabled people on staff. Mary Lou Breslin, for example, felt that it wasn't a good idea to have parents on staff. But once they came on staff, she became one of the biggest advocates for having parents on staff.

The advocacy component that Kitty and Hale and Karen Parker worked on. Greg Sanders and the work that they did on transportation, on benefits, on issues around county funding, city funding. Our job development program. The establishment of the computer technology program. There was a lot going on, and we really were—we were an organization that started out serving adults, primarily whose disability had been acquired when they were teenagers or adults. Then we really began to move into a more cross-disability organization that also was becoming more and more cross-age. We had always done some work with seniors, but even there we began to do some broader work. Work

that we were doing with people who had "mental retardation" and psychiatric disabilities. We were getting into the race and diversity issues.

We really were doing an incredible amount of work, when you looked at the complexities of the needs of disabled individuals, we were setting up a place where, in my mind, disabled people didn't have to go to all these different organizations. Then we also, when we got funding and were working under these different projects, we also then were working with lots of other organizations in the community, whether it was locally or more across the state or nationally, and we did things more boldly than many others did. Yet, I think we really touched the lives of so many people.

There was the work that we did in the state institution in Santa Rosa. The work with deaf individuals who were institutionalized, and helped get people out. The Kids Project that we did. I mean, the Kids Project: that was such a phenomenal project, because the premise that they accepted was that, well, we wanted teachers to teach children, but teachers couldn't teach the children until they were taught first, because they had biases that they would be instructing. So that we were able to do this eight- or ten-week training program for teachers and a separate program for kids was very powerful, I think. We were persuasive. A lot of disabled people in Berkeley at that time were voting. People running for government knew that they had to, on some level, deal with us.

Voice of people with disabilities

Heumann: You know, I don't want to paint a picture that everything that we were doing was turning the world around overnight, but what it was doing for us was enabling us to see that disabled people did need a voice that was controlled by disabled people, and the voice needed to be involved in lots of activities: policy, direct services, empowerment, legal issues, civil rights, coalition development, networking, straight up politics. The organization wasn't involved in straight up politics, but if you were an active member of the organization and you participated in things and they knew you were from CIL, that was also helpful.

I think some of us worked there because of the challenge of trying to get things changed. I think it was an opportunity for many disabled people to express themselves for the first time with the support of other people. I think for nondisabled individuals, my sense is that they too felt empowered in some degree with what was going on, that they were making a difference. You had sixties types who hadn't outgrown the sixties time period and were also into doing, would be interested in changing the world, so to speak.

I think CIL was also interesting because it was getting an incredible amount of attention. So people were coming from different parts of the United States and different parts of the world just to look at what was going on and how was it going on. I think that was empowering.

We did a lot with a little, and I think sometimes people felt good about that, and later on people might have even resented that we did a lot with a little. Or they maybe didn't resent that we did a lot, but they got a little. I mean, I worked there for years on my SSI, I

had $200 a month. We didn't have a real difference between the salaries, of the director and others there.

Yes, I think those are some of the main reasons people worked there.

Why this specific group of people worked at CIL

Brown: Why was it those people?

Heumann: When we had money to hire people, more people came. We had, as I said, 200 employees, and that didn't include the personal assistants that worked with people, because they were hired by other people. So could we have continued to find more people, if we found more people, if we had more money? Yes, because we also had a lot of volunteers. You know, we had the board, which was volunteers, and the Friends, which were volunteers. It was a real cross-section of everything. I think when you look at the 504 demonstrations, which we'll talk about at another time, but what was interesting about those demonstrations was, you know, you had the Black Panthers through Safeway. The governor to the mayor, city councils around the state, to this hobnob group of people.

I think people felt good—some people felt good about being able to make a difference. I assume on some level, for some people, they might have had a sister or a brother or a cousin or a friend, or they just saw Berkeley and the surrounding community as a place that was supposed to do things different and more progressive. I think frequently, those of us who had to work with other nonprofit groups, or with government entities, would be frustrated by the fact that we had difficulty making some of the changes that we wanted to make.

For example, for CETA money, wanting to have a requirement that CETA—other grantees who had CETA funding would have to keep data on the number of disabled people that they serve. We had felt that we had no difficulty keeping data on race and sex, but we wanted disability to be a part of it, because other organizations weren't being held accountable, and we knew that they weren't serving. One of our goals was to have other organizations be working with disabled individuals, that it shouldn't just be CIL doing that.

I think here you were making a difference, and it was a very empowering place at that point, when you could come in almost any day and there were always people there. The place was not renovated yet in the back, so we had—I don't know, it was pretty informal, which I think was also good. I believe that many of the people who were receiving assistance from CIL one way or the other by and large felt comfortable that they could come, and they wouldn't necessarily have to have an appointment, that they could just come and talk.

Now, again, people would complain about that. They didn't have enough space to work in, it was noisy, da da. But for me, it was an incredibly electrifying place. I think it's why 504 demonstrations were able to be the way they were. I think CIL played a very strong role.

— 367 —

An amazing group of people worked there. I mean, when you think about it. Just Arlene [Mayerson] and Diane [Lipton] and Julie [Landau] and Paul and Bob Funk and Mary [Lester] and Lynn [Kidder] and Phil [Draper] and Ann Cupolo and Phil Chavez and Ann Steiner and Joni Brevis and Neil Jacobson, just had this cross-section of people. You also had people from the far left—there was nobody to the far right. You had people from the far left to the moderate. [laughs] You nearly could call them conservatives.

Common philosophy among staff

Brown: This might be a good place to move into that. Was there pretty much a common philosophy among CIL staff?

Heumann: I think while we argued around structure, we'd have meetings going on about management style, should we have hierarchical versus circle versus whatever. I think if we could put those things to the side, you know, people complaining about how the organization was managed, on a philosophical level, I think there was agreement, that disabled people had the right to be empowered and set their own agenda, and that CIL was an organization or the organization that could really act as a support, encourager, place to help things work. Yes, I really do believe that if you could put some of these other things to the side, that by and large, people definitely sort of valued the place, and felt good about being able to be a part of it.

Brown: Did it seem to you that there was a party line?

Heumann: I mean, should buses be accessible? I don't think there was a party line on that. I don't think there were differences. There were little differences—should we run a paratransit system or not? But it was remarkably noncomplicated. For example, before I came there, the decision that had been made that CIL wouldn't develop housing, because what CIL was trying to do was do things that others weren't doing. I thought that was great, that they had come to that decision easily. I think we could have discussions about politics. I mean, at some point, the board didn't want to serve psychiatrically disabled people. So then they overturned the board.

Brown: Why did the board not want to do that?

Heumann: They felt we were expanding too fast.

Brown: So they just decided that the best thing was not to serve them?

Heumann: Not to do it now. We weren't really serving at that point. Some of us were trying to continue to open the door, and if we were going to serve individuals with psychiatric disabilities, then we needed to have disabled people with psychiatric disabilities involved. We also needed to train staff and get staff assistance in working with people who had that type of disability. I think we had good grant writers and we had good ideas, and we could continue to move forward, trying to expand our program to be able to benefit more people. Certainly there would be times when we would go someplace, "This is what we're going to say," but as a rule, with those types of things, no, there wasn't—as a rule, you didn't have people disagreeing. I mean, the need for accessible housing, the need to educate landlords, the need to get money to make things accessible, the need to have people be able to get their benefits, the need to get personal assistant services where you were in charge.

Starting from zero

Heumann: At that point, we weren't at the more complicated levels of discussion: should we file this lawsuit, and what was the implications if you did if it was a bad case? We started almost at zero, is the way I look at it. We started almost at zero. So we had a pretty long way to go before you got to the conflict area. You know: should people come out of institutions? Well, yeah, you had people who were afraid that we couldn't necessarily do the work, but then you had all these other people who were like, "Go for it." So what am I going to say, no?

That's what I thought was great about it. There was a lot of permissiveness. I did, I should say for myself—that we were a very powerful group, and we could put forward lots of people at meetings. We could easily organize thirty to fifty people for something. You might not have felt easy while you were doing it, but—you know, we had people like Kitty Cone who were phenomenal organizers.

But because people were more involved, because they were there and they heard, it was also easier to get people to come out. Because people were still fighting to become a part of something.

High level of optimism and energy

Brown: It sounds like a very energetic, optimistic place. Can you talk about that a little bit? Did it always seem that way?

Heumann: No. I mean, people legitimately were wanting better management style, but we were working on doing that and—you know, for myself a lot of times, the train kind of keeps going. To me, it was, don't lose opportunities. So we would have consultants coming in and helping us with management. That's sort of similar to what's been going on where I work right now but on a smaller scale. I think it was appropriate for people to want to have a—to know who they had to report to and what they had to report on, who handled time sheets, and cope with accounting and all those things. The bigger we became, the more sophisticated we became.

I think a lot of people had optimism, and there was an incredible level of energy. I think the more we worked together, and the more we became inclusive of a broader population of people, I think—again, for myself—the more I just realized what a powerful concept this was. I remember sometimes in the beginning, you would hear people talk about—not at the center, other places—CIL was run by Communists. People who weren't grateful.

Brown: Grateful in what sense?

Heumann: For what the system had given them, and clearly look at what they were, and they had—. I remember having a discussion one day with somebody from the outside who said, "Wasn't CIL a sheltered workshop?" I said, "No. You know, the difference between CIL and a sheltered workshop is that you have a choice to come in or to leave," and that we didn't earn sheltered workshop wages. I said, " I think this choice issue is really important, because in other places, disabled people had no choice as to where they wanted to work. If the choice was staying at home or coming to a sheltered workshop every day, they'd likely go to the sheltered workshop just so they get out of their house."

I remember when this guy said that. It's an opportunity for people to upgrade their skills, to really believe that you could make a difference. It's kind of fascinating: the numbers of projects. The women's project, we had a youth project, I mean, it was just phenomenal. I would say by and large, all of the programs did a great job. They met their goals and objectives, they went beyond what they needed to do, or what they were expected to be doing. They had an impact, they had by and large a commitment to go further—the status quo was not considered acceptable. It was pretty amazing.

I had a similar feeling when I worked in New York with Disabled In Action, and I think that was something that was happening in groups all across the country, where finally something had happened where, when we got together, we felt that we could make a difference, and we were. We recognized, I think, that we had put a lot of weight into traditional organizations, but that the goals of the traditional organizations were not the same goals that we had. I think it was a sense of maturity, really, that we recognized that we didn't have to depend on the goodwill—

[Tape 25, Side B]

Heumann: It wasn't getting us what we needed, and that we needed to create our own agenda, which other people were welcome to join. But that we were creating our own agenda. That we were willing to take risks. I think that CIL was certainly one of the organizations that played a very important role in that.

Disability-specific issues

Brown: Now at CIL in particular, was it your sense that it was a very cross-discipline organization? What kind of disability-specific issues were there?

Heumann: Certainly blind employees wanted to continue. We had a blind services program, and that was, I believe, the way of getting blind people to become a part of the organization. While blind people had the ability to participate in anything going on within CIL, there also continued to be a blind services program, which I think spoke to the politics of making sure that there was an identity within an identity. Deaf services being the same thing. I mean, you could argue you didn't need blind services, you didn't need deaf services, you needed to make sure that each one of the offices could specifically assist people. But then I think there were issues like mobility instruction, and I think you saw that sometimes

blind people wanted to be with blind people, and deaf people wanted to be with deaf people. But they had the ability to also be across the organization.

Brown: Did it seem to you that the blind people that were in CIL felt like they were a part of a disability movement?

Heumann: There would certainly be times when blind employees or deaf employees would complain that something hadn't been done the right way. But as a rule, what was going on was people were coming to CIL for CIL to expand services. They weren't leaving CIL and saying, "You were doing a terrible job, we don't want to be here any more." That really happened more after the budgetary issues and there was a different phenomenon going on.

I don't believe it really was around categories of disability. But certainly I think as we moved into doing work with greater disability diversity advocates, and we were expanding our board to get racial diversity advocates on the board, I think having that done the right way was something that we were learning. I think some of the stuff came very easily, because those of us who had disabilities that could benefit from the changes there—this was like our little chemistry lab. But as we got broader than our sphere of knowledge, then we had to learn more about what to do, how to do it, and make a commitment to why we were doing it, that we really did want CIL to be a truly cross-disability, cross-age-group.

Deaf people, there was a little bit of issue, but very little. That was really more discussion around the fact that there was a deaf organization in the community to take care of them, and should we be wanting to do this? But there my recollection was we talked about the issue of choice, and that's when we set up this advisory committee of ten deaf and one hearing father, and the purpose was to really look at, I think, what the community wanted and what we would do. That's what they wanted, and so it was like it really wasn't our place to say no, because CIL was offering more than, in some aspects, what this other group was saying it was offering.

But I think the bottom line was, people have a choice, and nothing precludes you from going to DCARA [Deaf Counseling, Advocacy and Referral Agency] and going to CIL.

Brown: But I think I'm asking the question the other way. Not did deaf people want to be part of CIL and its disability movement, but did the people that were already there—.

Heumann: That's what I'm saying. There wasn't really that big a deal around it. It was, Before we do it, let's do a study group, let's look and see what—. I really don't recall except, as I said, when we moved forward to psychiatric disability group. A little bit with the developmentally disabled population.

Brown: Were people thinking, "Oh, but they're not disabled, or they're not our kinds of disabled?"

Heumann: No, it had nothing to do with whether they were disabled or not. I think it had to do with were we going beyond what we were capable of doing, and people were worried about, could we do what we said we were going to do, and if we couldn't, what would happen? Some of us felt we could, we'd learn, and we should.

— 371 —

Learning as they went forward

Heumann: So there was an ongoing learning experience that was happening. Because remember, there would be people of different types of disabilities working in the different components. There were nondisabled people working there too. I think people developed a broader group identity each time another group came in. We learned about issues of parents, and we learned about issues of abused women—so all these different facets that people didn't typically talk about under one umbrella, that we were trying to resolve—I kind of feel like what we were doing was trying to really, as quickly as possible, change infrastructures, externally.

Okay, if the schools are going to be accessible to people, we have to help change the infrastructure. Albeit we knew that this one project couldn't do all that, but if you look at things that we went forward to do, in the housing—[telephone interruption]—I think if you looked at the friendships that were created, I think as an organization we were more quickly able to learn about issues affecting other people and work on making the organization and people feel like that we belonged, than if you look as a rule in the general population. Things like deafness and sign language. Well, we kind of did things, you know. We had sign language classes. Then for a while, as we were getting bigger in particular, we had people who didn't really know about disabled people, different types of disabilities. We ran these discussion groups where people could come and present on who we were and very basic 101 stuff, because we had this cross-section of people there.

Brown: Was that sort of a requirement, or more like a brown-bag kind of get together if you wanted to talk?

Heumann: Yes, it wasn't a requirement. People would just come. I think we were limitedly successful in working with individuals who have cognitive disabilities. So during the time when I was there, we were slowly doing more work in that area. I think they've done more work since then.

I think that there was very much a commitment to each other, and even though we were learning as we were going on and not everything was as easy as you always wanted it to be, I think in the long run, there was this commitment to disability. I mean, we were involved, for example, with the discussions when the 504 regs were being done of should substance abuse be considered a disability. I remember that we spoke very strongly that we felt substance abuse needed to be considered a disability, even though some people felt that it was "self-inflicted." But we already had people working in the organizations who were active substance abusers or recovering substance abusers, and it was very clear to many of us that, of course, they should be covered.

Why good people stayed

Brown: Why did employees stay? The question is, why did good people stay at CIL? What kept them there?

Heumann: I think it's what I've been saying: there was a belief that you could make a difference, and you had people who had similar views and concerns as you, and you were—I don't know, I don't know if anybody else would say this, but for me, I clearly felt like we were making history. There was something going on. Even today, when you talk about the 504 demonstrations or I meet people, "I was in the building," there's this real sense of ownership and pride that you were a part of something very important that happened for yourself and for other people. I think it wasn't the wages. I know one thing: it was neither the wages nor the benefits that kept people there for long periods of time.

I think the other thing was that for myself, I wanted the more creative the person, the better, for me. I did want people to be able to be self-directing. I don't mean completely self-directing, but I did want people who were idea persons, who could try to shape those ideas. So I was looking for innovative and creative people. The more innovative, the more creative, the more interested I was in them. People who were willing to challenge the system.

Why employees left

Brown: Why did employees leave?

Heumann: I think employees left for a number of reasons. Some people didn't like the fact that the management structure wasn't what they wanted. They didn't fit in to that environment. They weren't necessarily, in my mind, high enough achievers. They wanted a better wage, they had a family. They wanted a more traditional environment. Went back to school. Got a better job. But if you think about the core of the organization, they were there a long time. [chuckles]

Looking at Phil, Phil was there until the end. Ed left for another job. See, I don't know what would have happened had we not had those financial problems. Had we been able to mature into being a better-run organization. I have never been of the mind that it was good that DLRC, the Kids Project, et cetera split off from CIL. I understood why they did, but I never felt it was in the best interest of the community. Competitive organizations were being set up. The work was less focused on what was best for individuals and the community as a whole.

Because you see what happened, there are all these different groups and they all have their own egos. Now, there was competition for money within the organization, so it was very clear that we made people go through a process. People couldn't just go out and apply for money without getting clearance on it, getting grants approved. The bigger we got, the more structures clearly were put in place. But there was still one management, and there was still one goal. Every time you set a group up, its goal becomes more narrow, although maybe—because the entire purpose of the organization, it can spend more time thinking about one issue. I don't mean one issue, but one aspect of an issue. One aspect of the needs.

Ms. Heumann's typical day at CIL

Brown: I'd like for you to describe for me if you can a typical day at CIL, first of all when you were in the office.

Heumann: The first year I worked at CIL, I almost literally worked seven days a week. Typical day—oh, God. We were always busy. We were either making phone calls, had meetings on projects, talking about what people were doing, what their deliverables were, where we were, what we needed to do to do better, working on legislative issues. I mean, it was like an office. So it was any—could be out talking to foundations, could be out going to meetings, about county issues, city issues, state issues. I've never been one to have a lot of down time.

Brown: How did you keep track of your schedule?

Heumann: At that point, I could do it in a day-at-a-glance.

Brown: Oooh!

Heumann: Did day-at-a-glance until I came here. Typical days. Typical days—busy.

Brown: What sort of hours did you keep? Or how did you get to work?

Heumann: I always lived close to the office, so I either walked up the block or, when I moved to Regent Street—but I was always close, which was great. Didn't need a bus, didn't need a train. Usually I left at five. Especially in the beginning, really. The first year I was there, I was there six, seven, eight at night, and I worked six, seven days a week. Until I totally fried my brain. One year of that, and the intensity of CIL was like, Uhh. No, I've pretty much been a habitual workaholic. It was nothing different working for CIL, when I was at CIL, and when I left CIL.

Brown: How did you have time for personal activities?

Heumann: Well, you know, there was—you know, we did. We would do things together, like we would go out to dinner, go out to lunch. We wouldn't go out to lunch every day, but I went out to lunch—. I mean, I'd be invited to people's houses, have people over to my house. Yes, and we would go to the movies or go out dancing or—. There were different meetings to go to. I was also on the boards—I mean, I was on the ACCD [American Coalition of Citizens with Disabilities] board. I was very involved with the state Independent Living Coalition.

Brown: Were most of the people you spent time with socially also connected with CIL?

Heumann: As a rule, really. I didn't socialize with everyone who worked there, especially as the organization got bigger. I didn't socialize much with Phil. That was really more because of Sharon, his wife.

Brown: Do you want to say anything more about the typical day in the office, or do you want to move on?

— 374 —

Disability simulation experience

Heumann: I think not much more to say about the typical day. I know what I wanted to say. We had this one project, Peter Leech. It was this great project. We had counselors, I think from Region 9, and who were working on getting nondisabled individuals to understand the disability experience, albeit in a very limited way. What was interesting, so many of our projects I felt were very interesting. Because it wasn't this, stick somebody in a wheelchair for two hours and let them understand the world. But they came to us for like a week, and started off with a day, at least a day of discussions around disability. Then the persons assumed a disability for like two or three days, and they lived in the house of someone who had that type of a disability, so they were learning from that other person. Then there was another one or two days of talking about what the experience was like.

So that was kind of interesting, and certainly a lot of people wouldn't do that. But I always thought that was interesting, because there was enough time that people had to begin to think more in depth about what the experience was like and how people were treating them, what they could or couldn't do, but certainly wasn't very long, so they also knew that they were getting out of it. But I think it was an opportunity for people who wanted to get a little bit of education, to get a little bit more information, to at least be a little bit more understanding of what some of the broader issues were that we were discussing.

So back to a typical day?

I would meet with Betty or Mary or Lauren, who was my assistant at the time. Tried to deal with mail—we had to deal with mail and answering mail and answering phone calls, and figuring out who was going to be responsible for what. There was a lot of fund-raising, overseeing services, and government relations. Did a lot of the government relations work; certainly not all of it, but especially federal. City, more people were involved. State.

Typical travel day

Heumann: A typical day when I traveled: it depended on what I was traveling for.

Brown: What were some of the reasons you traveled?

Heumann: Talking about CIL, what it was, what we were doing. Doing trainings for people. Speaking at conferences on disability rights issues. Going to meetings.

Brown: Who were your audiences for these trainings?

Heumann: For the trainings, it was typically disability groups. For the speeches, it could be a whole variety of groups. I was on the National ________ Association board. Coming to Washington, ACCD board meetings I came to, numbers of times a year. Meetings on the 504 regs. Kitty, I think, attended more meetings on transit. Those types of things.

— 375 —

Brown: Would you come to D.C.—was it mostly D.C. travel, or really all over?

Heumann: I did a fair amount of D.C. traveling, but I went to Boston and to Syracuse and to Illinois and Colorado and Texas, lots of different states.

Brown: Did you do international travel?

Heumann: Yes. I started doing international travel, as you know, in '72. I really didn't do that much international when I was at CIL but did a lot when I was at WID. So I mean, when we went back to Washington for the 504 demonstrations, there were typical days. Then when I went back just for regular activities, there were typical days.

Brown: Did CIL pay for your travel or other people?

Heumann: As a rule, CIL didn't pay. We didn't have the money. I was involved with the White House Conference on Handicapped Individuals, which preceding that was this gay conference. I was on the Architectural and Transportation Barriers Compliance Board, so I came back for meetings on that. I was on the Presidential Women's Committee that Bella Abzug was on. Let's see, I was appointed—Cranston had me appointed to a lot of stuff. I was appointed to the Architectural Barriers Board, I was appointed to the Women's Committee, I was appointed to the National Council on Disability, I was appointed to the President's Committee, vice chair. I was on numbers of those federally, so I really did a lot of travel with all those, and they paid. [noise on tape]

When I worked at CIL and when I worked at WID, as compared to my job right now, my travel was different, because in this job, it's like I need to be out there meeting as many people as I can, visiting programs. In my other jobs, typically when I would go, I would be at meetings. So I could spend—I would go to a meeting, I would be there the whole time. So it was very different. Although sometimes, again, depending on what you were in town for, you went to a lot of different things. But as a rule, it wasn't that many in a day. It wasn't as complicated, travel arrangements.

At OSERS when I traveled, I was required to do many activities in a day. Many different sites might be required. When I traveled for CIL and WID, more likely I was attending a meeting and I stayed at the meeting.

[Tape 26, Side A]

Brown: Did you get to choose what you wanted to work on?

Heumann: Sure. I mean, the law program worked a lot with me, it worked with Phil also. The manager of services met with me and met with Phil. I met with—you know, we would have these ongoing issues of, you're going to supervise this and you're going to supervise that, and then sometimes we did it that way and sometimes Phil would talk with them or I would talk with them. I would be on travel, he would meet. Certainly, because I could travel a lot, as always. People would need to work with Phil.

Phil took the primary lead in like the Friends, although I was definitely involved in the Friends.

— 376 —

Brown: Did you work in anything that you were not interested in working on because there wasn't anyone to supervise it?

Heumann: We had like a director of services, so the director of services and I would meet, and I'd meet also sometimes with the projects. No, I was interested in most of the things going on there.

Development struggles of a nonprofit organization

Brown: In general, did most CIL staff get to work on things that interested them?

Heumann: Most CIL staff applied for a job in an area. I mean, as the organization got bigger, they were applying for a specific job. So they were working in peer support or in attendant referral or blind services. One of the issues that we were dealing with then was getting the components to work together, so people—that's why the central intake was important, because we were developing coordination to make sure that individuals knew what they needed, and we were helping make sure people got what they needed.

I mean, I think on the one hand, my job, I liked my job because it really gave me a lot of opportunity to be creative. Really, CIL was integrally involved in getting the state coalition set up, getting the state—Tom Bates legislation passed. We were integrally involved in getting Title VII provisions in the Rehab Act, and having the hearings that were held prior to that occurring. All those took lots of time. So we were very actively involved in getting the transit authority to change its policy so they'd buy accessible buses. Kitty, you know, was the lead on that, with Hale and stuff, but I was definitely involved in working that. We had the 504 activities that were going on, that took a lot of work for a long period of time. Once we were successful at that, then we were working on the contract that would have to do training on 504. Which again was mainly handled by Mary Lou and other people, but I was involved in that.

Would people be involved in what they wanted to do? On a certain level, people had to do the job that they were hired to do. But because we were a pretty collaborative organization, they had an opportunity to learn about things going on in different areas. They weren't like tied to their seat. Not everybody wanted—I had a friend who described me once as a pentathaloner. Not a lot of people want to do that. I like having a lot of balls up in the air.

But on a certain level, except for the money, I think people had opportunities. I mean, the organization, it was still growing when I was there. It wasn't growing necessarily in size, but in maturity and development. I would be lying if I said—if I didn't say strongly that there certainly were things that could be run differently. But I think overall, before the financing became more problematic, there were opportunities for people. There were committees, and all types of activities that people could get involved with. We were in close proximity to many of the other programs. Although, of course, the bigger we got, even though we were on primarily one block, we had—Kitty could talk about this—we had facilities or space in numbers of different places. So the bigger we were, the more people were wanting to know—What are you doing? That's why we had the newsletters in all

these different things, because communication was a big issue. It just boggles my mind to think of all the things that were going on.

We went through a lot of the struggles that typical nonprofit organizations go through in development, in rapid expansion, in being more ideologically driven than organizationally-managemently driven. I think the atmosphere was intense but casual, and collaborative. I think people talked about CIL as an elitist organization. You know, when you talk about party line. Party line doesn't fit so much as an elitist organization. CIL thought it knew it all, and blah-blah-blah. Especially as the other centers would be developing, so you had those types of issues. But still, there was a lot of collaboration, because the organizations had similar missions. In the beginning, many of the directors were people who had been at Berkeley, been at San Jose, different university programs, knew each other from CAPH [California Association of the Physically Handicapped] or other organizations, and were all mentoring each other.

There was this sense of—We're CIL, we are better than you are. [laughing] There was lots of stress. I think the funding issue was just an ongoing problem, and it never got away from it. We were never over it. But we kept going forward. We bought the building. Of course, later on, they sold the building, had to buy the building back, because they needed the money. But now they own the building again. So that's all.

XVI. More Reflections on the Role Of CIL at Local, State, and National Levels

Congressional hearings on independent living held at CIL

[Interview 16: December 20, 1999] [Tape 27, Side A]

Landes: This is David Landes interviewing Judy Heumann, December 20, 1999, at the Waterfront Plaza Hotel in Oakland.

Judy, some time in 1978 there were congressional hearings on independent living held at CIL. What was the legislation that those hearings related to?

Heumann: It was during the reauthorization of the Rehabilitation Act. Check on the dates. When I had worked in Washington, I had made a lot of contacts with different people, and one of my purposes at that point was to try to get people more linked up with what was going on within the disability community. California had really been the state that was developing the most independent living centers, although there were centers that were being developed in

Massachusetts and Michigan.

But there was no federal funding. California was really doing two things, and I believe we were working on them almost simultaneously. California was working on getting state legislation, which we later called the Bates Bill, which was money for independent living at the state level; and then there was the development of the federal initiative in the Rehabilitation Act to fund independent living centers.

It would be good to get the record because I believe there was a formal record; there was a transcriber there. Jack [Duncan] was, I believe, the staff person who was there from Congressman's Bradamas's office. And then George Miller, who was and still is the congressman from Contra Costa here in California, and an Ohio guy whose name I can't remember, who was very conservative and has since passed away. But there was question as to whether or not that congressman from Ohio would be sympathetic to what we were trying to do, but he actually was sympathetic.

— 380 —

The purpose of those hearings was really to, from my perspective, establish the fact that there was a role for the federal government to play in funding centers for independent living, or independent living centers. Our purpose was to present people from an array of communities, not just the disability community, who would be able to talk about the purpose of the organizations and, most importantly, talk about how the centers had had influence at the local, county, and state levels which was resulting in the improvement of quality of life for disabled people through many different activities.

Landes: Who testified? Do you remember any of them?

Heumann: It should be in the book. The entire record will be there. But my recollection is that we had a work group that we had put together from California independent living centers.

Landes: And who do you remember having been on that?

Heumann: I think Brenda Premo was involved, Doug Martin, I want to say Bill Tainter; Ed Roberts was involved through the state agency; of course, Phil Draper, myself.

Landes: And so the purpose of this was to make sure that your message was getting across in the hearings?

Heumann: Right. We had a series of panels. We had a panel, for example, of independent living center directors. We had a panel that included, I believe, a parent and a child who had gotten services from CIL, which had helped them get better services from the school system. We had, I believe, a panel on employment. Or maybe not. We had a panel where we had representatives from the county government, and I think also from the city government, to have them talk about how the centers—in this case, the Berkeley center—had been influential in helping to change city and county policy to be more favorable toward the needs of disabled people.

I think we had a panel of disabled people who talked about how the services from the centers had been beneficial. We really tried to give them a very broad presentation. I'm trying to remember if there was one on employment. I would want to say that there was, but, again, the record would show.

I think those hearings were in part helpful to the degree that then there did become language in the Rehabilitation Act, I believe of '78, which set aside funding Title VII of the act. The end result really deviated more than what we had wanted. What we originally wanted was just money for centers. What the statute actually did was to provide funding for centers, provide funding for the older blind, and provide funding to the state departments of rehabilitation for the provision of independent living services.

Landes: Did you feel that those additions were good things?

Heumann: I really didn't like the addition of the funding going to the state agencies and not directly to centers because I felt that there was limited money. It would have been better to give the money directly to the centers because the amount of money they were going to get was going to be so small. But the state directors were, I believe, also afraid of the whole concept of independent living. Some of them—I don't want to put them all together, but there were some who were still—

Landes: You're referring to directors of the state departments of rehabilitation.

Heumann: Exactly. There were some who questioned the value of the independent living centers because at that point there really weren't that many of them. Of course, Ed as the state director was the one and Don Galvin, who was then in Michigan. Don and Ed, I think it would be fair to say, were the two state directors who were really doing the most in independent living because both California first, I think, and then Michigan second actually put money into centers before the federal government had a specific set-aside for independent living centers.

Landes: So to your knowledge, those two were the only two heads of departments of rehab that really saw the connection between independent living and employment of severely disabled people?

Heumann: Well, more than employment, I think the relevance of independent living programs to really help people get jobs, but also to be able to overall improve quality of life. Now, one of the first centers in the United States, the Boston Center for Independent Living was, I would say, probably around the same time as the Berkeley center; but I don't believe that the state director in Massachusetts—and I don't remember who that was at the time, actually—I don't believe that the state director took on the issue like Don and Ed did.

Landes: When you say at the same time as Berkeley CIL, that would be the early seventies, '72, '73.

Heumann: Right. I think when Berkeley got incorporated in '71 or something—'70, '71.

Landes: We can look that up.

Heumann: But there were a whole series—you know, as I said, the Boston center was about that time, and Gerben de Young and Fred Fay were very involved in it. I think it started out of Tufts [University], which might have been involved in helping to set up the one in Boston. But I think the Berkeley center was a little bit more progressive than the Boston center. But nonetheless, for its time, the Boston center was in the beginning.

Landes: You mentioned a relatively conservative congressperson from Ohio. Did you get any feedback from him—we can look his name up—but did you get any feedback from him regarding whether or not these hearings moved his position?

Heumann: I did from someone else. It might have been George who said that [the congressman] was very moved by what he had heard that day and was convinced—I think what he was moved by, probably, was we did our very best to get significantly disabled people to talk about how their lives were being changed. I'm trying to remember if there were disabled individuals other than the directors because all the directors, I think, that we had speak were disabled, but I think we might have also had some people who were employees or getting services from the centers speak.

Landes: Now, did this take one day or half a day, two days?

Heumann: It was only one day. I don't remember if it was a half a day or a full day. I want to say that it was a full day.

— 382 —

Landes: So did you consider it a successful hearing?

Heumann: Yes. It was a very successful hearing—I think for a lot of reasons. One of them was that we broadened it beyond just CIL. We talked about it across the state. I don't think we had anyone from Michigan there, but we were very much trying to make the case that this was something that could be useful in other parts of the country.

Landes: Then the outcome was incorporating some of this into the—

Heumann: The next reauthorization for the Rehab Act.

Landes: Is there anything else you'd like to say about those hearings? Any reflections?

Heumann: I think getting the record will be good because I haven't looked at it in twenty-one years now, going on twenty-two years. But I think it was important because of the diverse people that we had speak—you know, people with different types of disabilities from different parts of the state. And, as I said, we had government people and I believe employers, as well as disabled people, and I think we were able to really do something that doesn't typically get done. The fact that they had come out to California to the hearings, I think, was also very important.

The Bates Bill: state funding for independent living centers, 1978

Landes: You spoke about the Bates Bill. Tell me about what the Bates Bill was to do?

Heumann: The Bates Bill was intended to pass a piece of legislation that would provide funding to existing and to establish new independent living centers. It was to help assure the stability of programs, and it was to help provide funding which would focus on services, core services, which was somewhat similar to what the federal government did. You could get money, and the money had to be provided, I think, for services like information and referral, and peer counseling and advocacy.

The Bates Bill, again, was a very big coalition effort in California because it was all the centers that were working together. I think now it has really evolved, and there are probably somewhere between $8 million and $10 million a year that the centers get.

Landes: Now, was this 1978 also?

Heumann: I think they were all around the same time, yes. Yes, because the demonstrations were in '77, the 504 demonstrations, in '77. So '77, '78.

Landes: When you talk about building a statewide coalition to support the passage of the Bates Bill, what role did you play in that coalition, or anybody else that you worked with at CIL?

Heumann: Phil and I were the ones who I think significantly represented CIL when it came time for working on that legislation. I think I might have been representative for CIL.

Landes: What about putting the coalition together? Was that done out of CIL? Were you involved?

Heumann: I was involved, but I wouldn't say it was done out of CIL. I mean, I think we were a part of it. I think Ray Uzeta, Ray Zanella, Bill Tainter, Brenda Premo, Doug Martin—[whispers to herself] God, I'm trying to think—

Landes: So it really was a collaborative statewide effort.

Heumann: Anita Baldwin was involved. Yes, it was a collaborative thing, very much.

Landes: So that Bates Bill provided the money, and then has been doing so in the subsequent twenty years?

Heumann: Yes, and I think there are have been formula changes that they've made, but basically California was the first state to have a piece of legislation like this, and it may actually be the state that provides the most money. CIL helped New York, for example. Phil and I went out and did a training for New York state on independent living, both to try to help them get funding at the state level for independent living and also to help them learn more about the concept of independent living.

We were doing a combination of working within the state and working with other states. The American Coalition of Citizens with Disabilities [ACCD] had started a few years earlier, and I was on the board. So we were meeting people as a result of just what was going on in IL, but also as a result of some of the other organizing activities that were going on.

Landes: Was ACCD involved in helping to procure money for independent living centers?

Heumann: Not really. I mean, they may have done something. They certainly would have supported it. Frank Bowe, who was executive director, certainly would have supported it.

Landes: But they didn't play a direct role?

Heumann: I mean, you'd have to ask Frank. He was back in D.C., and to the extent that he would have been providing information on the Rehab Act, he would have been supportive of the IL money. But I don't think he played a heavy role in it.

Landes: Any other reflections on either the Bates Bill or the federal bill?

Heumann: Well, the Bates Bill, I think, was very helpful for a lot of reasons. It did really begin to make people in the state have to work more substantively together, both to look at the policy that we wanted the legislation to be advancing; but then we had to take responsibility to really get members throughout the state to understand about our centers and to understand why they should be sponsors and vote for the bill in the end.

I think it allowed us to do more work with Tom Bates and Dion Aroner. You know, Dion played a very big role in this. I think it really helped to solidify IL in the state because it was the first time we had ever gotten together to work on something that was specifically IL-oriented.

Previously we had worked together; it was on, like, IHSS or the supplement to the SSI benefit.

I think there were frictions and tensions that were going on as we were working on the formula—big programs, little programs. I don't remember.

Landes: Do you remember what those tensions were?

Heumann: They had to do around money—you know, how the formula would be developed and who would benefit.

Landes: Now, when you speak of a formula, would you describe what you mean by that?

Heumann: There was a formula that was developed to help distribute the funding, the state funding of independent living.

Landes: As to which centers would get how much?

Heumann: Well, it was based, I think, on the size of the budgets, of the centers. It was a combination of things. You know, there were a number of reiterations, so I'm trying to remember what the first iteration was.

Landes: Oh, I'm not asking for specifics, but just in general. So it was really the formula that would allocate monies to the existing centers.

Heumann: For the existing centers and to help establish new ones. There was a combination—basically, California started with Ed providing innovation and expansion dollars from the federal government to set up, I think, ten additional independent living centers. So when the Bates Bill was passed, we had state money that was going into ten programs and the Bates money which started coming in. So that was really important because there were two governmental agencies that were providing support for the programs.

Financial problems at CIL

Landes: Okay, we've been talking about money and money and money. Money problems seem to have been a fairly consistent problem at CIL from the beginning.

Heumann: I wouldn't characterize anything that we've just discussed that was money problems.

Landes: Money in general. But that we've been talking about money.

Heumann: Yes.

Landes: There was always a financial pinch from the very beginning. But when did the financial problems seem to worsen?

Heumann: Well, when I came to CIL in December of '73, I had no idea that there was a deficit within the organization. Ed—Ed—love him!—he—

Landes: He was an idea person, not an accountant.

Heumann: Well, he had good—Ed was no slouch in any of this. He definitely was an idea person. He didn't necessarily pay attention to detail, but when he did, he understood it, so that I think is an important distinction because there are some people who, when they pay attention, don't understand it. So he had the acumen to be able to do that.

I went on the board in '73, when I came out to California, and then I left. I was still on the board, though, when I was in D.C. When Ed became the state director and Phil became the director of CIL, then they offered me the job as the deputy. I had a paid job in D.C.

Landes: You spoke about that.

Heumann: Yes. So I didn't know two things: one, that the money really wasn't going to come through for the salary; and two, that there was already a deficit within the organization, which at that point was about $50,000. I think that deficit had really—I think what was important about all of it, as I have said earlier, was that there was never a question of anybody doing anything inappropriate with the money. It was an issue of—

Landes: I think that's been clear.

Heumann: Yes. I think—you know, basically they had gotten somebody in to do the books who was neither a bookkeeper and had a drinking problem. I think they got technical assistance from the regional Rehab Services Administration to help deal with things, but there you were. Basically, I think the deficit really, you know, was never in the realm of the size of our budget. I think the deficit was, at the most, $100,000 to $150,000.

Landes: What time period are you talking about?

Heumann: I guess from '73 until—

Landes: Until the eighties.

Heumann: Yes. It would go up and down. The problem would get more under control and then—

Landes: Do you have any feelings as to when it became of crisis proportions? Or why?

Heumann: We were doing a lot. Phil handled the budget a lot more than I did. But we basically never caught up. I mean, we never were able to get enough money in reserves that we weren't having to keep moving money along. It got to a point—you know, there were ebbs and flows, so there was the one strike, but there was concern that was brewing over—the last couple of years that I was there, there were times when payroll would be late.

Landes: So we're talking eighty-one?

Heumann: Yes. I guess it was in '81. We had bought the building in the seventies, and they had to sell the building because they needed the capital—they needed the cash.

Landes: For an IRS problem, as I recall.

Heumann: I don't remember. IRS. Really? Because we didn't pay taxes.

Landes: Payroll taxes.

Heumann: Right, payroll taxes.

Landes: Now, Proposition 13 was passed in June of 1978—.

Heumann: But before that—

Landes: Go ahead.

Heumann: I think, you know—and I probably talked about this before, but nonprofit organizations in general, striking that balance of bringing people in from the beginning who have got both the ability to create a vision and manage an organization—well, I think is very difficult. Typically, people who are more activist in orientation are not necessarily the people who are best able to really handle accounting, and I think that was a conflict that we had from the very beginning.

I think we were still very much dealing with the fact that the organization was both new, but also trying to convince people in the community of its value and the reasons to invest in it; and, then the population of people that it was serving were not people with money to assist it. So I think if you look at other movement types of organizations, you probably had a wealthier base of people to call on to help contribute.

Landes: But the problems CIL was having were certainly not unique to CIL.

Heumann: No, exactly.

Landes: So Proposition 13 passed in 1978. Did that impact state monies at all?

Heumann: Not—

Landes: That was related more to city and county taxes, I believe.

Heumann: Yes. Certainly, I think it had an effect on the county money, but not immediately.

Landes: So it was indirect at CIL.

Heumann: Well, CIL got money from the county.

Landes: Yes, so that it pinched the county budget, and they had to cut back services.

Heumann: Yes. I'm trying to remember when the services first started being cut back. It may have been as early as '78, '79. Then, of course, you had Reagan coming in in '80, where he block-granted programs and cut out other programs, and then you had [Governor George] Deukmejian coming in in '82. CIL by '81 had gone from about two hundred staff to about thirty.

Landes: In what period of time?

Heumann: A very short period of time.

Minority youth training project

Landes: Because of all the cutbacks.

Heumann: Right, because there were just major cutbacks coming on everywhere. There were a series of things that were happening. There were grants that were expiring that weren't being renewed because there wasn't support at the federal level to renew them. There were grants that we couldn't get funding for because they were more innovative kinds of grants. You know, I think I talked about the minority youth project, which to me was a perfect example. We had federal money for a minority youth training program. I think it was a five-year grant.

Landes: Do you remember what years, when you first got that money?

Heumann: Maybe it was a three-year grant: '77, '78.

Landes: What was the purpose of that grant?

Heumann: That grant was basically to work with minority youth and their families, to get the kids to stay in school, to get work experience, and to move into higher ed or employment. We had—gosh, the woman who ran the project was an Asian woman, had one arm, very long black hair. I can't remember who else. I can't remember her name. Michael Winter had a lot of involvement with that program.

[Tape 27, Side B]

Landes: We're talking about the minority youth program.

Heumann: Do you have records on any of these?

Landes: I'm sure there are records. Hopefully, we'll find them! Talk about the goal of that program.

Heumann: There were a couple of goals, but one was the way for us to also begin to do more work in the minority community, which we wanted to do because the organization when it started was basically started by white disabled people, and we were recognizing pretty early on that we wanted to diversify what we were doing.

Landes: Who was involved in really pushing that as an agenda for CIL?

Heumann: I was involved, Phil, Michael Winter, the board. That was just pretty much general consensus. When did Gerald [Baptiste] come on? Gerald came on—do you remember what time he came on?

Landes: No, I don't.

Attempting to serve a more diverse population at CIL

Heumann: But the thing about CIL that was great was we were always looking for—some people, of course, would be critical, but my goal was to continue to push it out, to serve more populations that we weren't serving, and that was by race and disability and age.

Landes: You've talked a lot in previous interviews about the cross-disability and expanding blind services, deaf services, people with mental disability—

Heumann: Psychiatric, yes.

Landes: What about age?

Heumann: On this particular project?

Landes: Yes.

Heumann: I think that the value of this project was that the staff, I believe, were almost exclusively minority individuals with disabilities.

Landes: Do you remember names?

Heumann: I want to say Grace is one of them, but I could be really wrong. I think there were, like, three to five staff. They may not all have been minorities, but most of them were. They went into schools, they worked with employers, they worked with parents, they worked with the youths.

Landes: From your viewpoint, was that a successful program?

Heumann: It was a very successful program. We, as I remember, met and exceeded our goals. The program that we were funded by out of D.C. was always very satisfied with the work that we were doing. ______ ran the project out of D.C., was an African American woman. We were one of the only disability projects that they had. There was a category of dollars that were put out. [whispers to herself] God, I have to remember these people's names. [normal voice] Carolyn was the name of the woman, I think, from D.C.

Landes: Was there an effort—

Heumann: P, P, P—Pezotti, Penotti—

Landes: We can think of the names later.

Heumann: I know, but you know, once you get on thinking of something? Sorry. [laughs]

Landes: Was there an effort at the same time to recruit more minority staff members in positions other than this particular project? Was that a spoken goal at CIL?

Heumann: Spoken goal.

Landes: Or was that a goal?

Heumann: It was a goal. So when we were doing our hiring, you know, we were recruiting for people who came from diverse backgrounds, both from a race and a disability perspective. One of the things was, I think, for the organization that there was always pressure on it to do more, and there were more things that it could do because it was really an opportune time. There were all these different things that were happening. I did describe it previously as kind of being a kid in a candy store. We were able to pluck a lot of apples off of trees to begin to get work done that, had we been more conservative in our approach, wouldn't have happened.

So I think there was a value in creating the number of things—DREDF actually wouldn't exist if it wasn't for the impetuousness of those of us who worked in the program because—

The Disability Law Resource Center

Landes: When was the Disability Law Resource Center [DLRC]?

Heumann: I want to say we did it in '77.

Landes: Was it before or as a result of the 504 demonstrations?

Heumann: It wasn't the result of anything. It was the result of a CETA grant being out, and Bette McMuldren and I sitting down and talking about doing it. You know, it was one of these things where I heard this grant was coming out, and we thought about it and worked on it. Bette was great. You had people like Bette McMuldren and Mary Lester and Joan Leon and Phil and myself who really, I think, clicked together—and Lynn Kidder, certainly. I'd say Mary was a more cautious person in the group.

Landes: In what sense?

Heumann: She had been around from the beginning, so I think she had seen the implications of the fiscal problems, so Mary was—and she worked with Phil and so, you know, she saw on a regular basis the tensions that were continually being developed by our expansion.

But when we applied for the CETA money to do the paralegal program, that was very much because we had continued to identify issues that disabled people needed lawyers for. Except for Legal Aid, which at that time—way before all these cuts came in—was already strapped—Legal Aid did represent us on numbers of things, particularly around transportation and some of the Social Security issues, but they couldn't represent us in everything that we needed to be represented by. When we had tried to get lawyers to help us from other firms, we didn't really have either the people to help cultivate relationships because the firm typically didn't really want to represent disabled people. So when we went for the CETA money, it was really [so] that we could set up our own legal program that could both help disabled people get jobs by being CETA employees, at the same time that we were helping disabled people get legal representation.

— 390 —

Landes: So I take it you played a key role in the development of DLRC.

Heumann: Oh, yes, yes.

Landes: And who else? Who did you work with?

Heumann: Oh, my God. Well, Phil was certainly involved. Jeff Moyer, I believe, because he was—I think Jeff was—maybe Michael Winter.

Landes: Michael Winter?

Heumann: I think so. But truthfully, there would be no DREDF if it wasn't for that grant, because then we got another grant. I think we got a Legal Aid grant, which was when we needed to hire an attorney, which is when we found Bob Funk.

Landes: So this is, you think, late '77, '78?

Heumann: '78, '79.

Reflections on the transition from DLRC to DREDF, 1979

Landes: When did DLRC become DREDF?

Heumann: I want to say their incorporation papers came before they split off, so the incorporation papers—well, they just had their twenty-fifth anniversary, right? No, it couldn't be the twenty-fifth anniversary. They just had an anniversary. Which was it?

Landes: Maybe their twentieth.

Heumann: Was it their twentieth anniversary? I don't remember.

Landes: Well, let's talk a little bit more about DLRC.

Heumann: Jim Pechen.

Landes: The role that you played in DLRC. Did you have an office in DLRC?

Heumann: We only began to expand—that's when I moved my office across the street.

Landes: So across Telegraph Avenue into the DLRC offices.

Heumann: Remember, we got—you wouldn't remember. After the 504 demonstrations, they put money out to do 504 technical assistance. We got one of those contracts. We got money from one of the other federal agencies to do a women's program, to do a report on, I think it was, the women's economic agenda project that we had gotten funding for because I had met the director of the program, and he had given us the small amount of money. Corbett O'Toole, I think, had worked on that grant.

Hale [Zukas], Karen Parker and Kitty Cone moved across the street because we moved the advocacy activities across the street. We had DLRC, we had my office, we had—

Landes: When you say your office—

Heumann: As the deputy director.

Landes: Why did you move across the street? So you would be in close proximity to DLRC and advocacy because that's a lot of what—

Heumann: It's one of the areas I supervised.

Landes: Yes.

Heumann: But I think it was very interesting to see the range of programs because you had the whole development of this legal arm, which was then doing parent advocacy because we got parent advocacy money. So we hired parents or advocates who later on—you know, like Diane Lipton, who went on to become a lawyer and was a parent, and Julie Landau, who later went on to become a lawyer. Arlene was hired as an attorney, and Paul was hired—who was an attorney. We had hired Bob Funk. Wait a minute. I meant Bob—this is on the tape, right?

Landes: Tell us how you found Bob.

Heumann: We got money—I'm trying to think if it was Legal Aid money. We needed to hire an attorney, and I just started calling all over the place to try to find somebody. I called a woman whom I had met years ago, named [Nancy Amaday]. When I met her, she worked for George McGovern, but then she had left and was working on, I think, a food program. I said we were looking for a disabled lawyer to help this project, and she said, "Oh, I have a friend. He's kind of like"—what did she call him?—her son or her brother. He went into the Peace Corps, lost his leg, went to Davis, and was just graduating from Davis and was looking for work. That's how I found Bob.

Landes: What was your relationship with Bob? Did you work well with him?

Heumann: Yes. I mean, Bob's a guy [laughs]. Bob was a closed kind of guy in a lot of ways, so I think Bob was working on the development of DREDF. We had meetings about it; we talked about it. He definitely felt that they needed to separate.

Landes: Why did he think they needed to separate? To your understanding.

Heumann: I think it was a number of things. One, I think the fiscal issues were definitely a part of it. He felt that the organization was being strained too much and it was fiscally a good thing to do to separate the groups. I think he felt that it was easier to run if the organization became smaller and it was more manageable to break the organization up.

But there was also a need to create a national civil rights legal defense fund for disabled individuals, that CIL, I think he felt, was a local organization, not a national organization, and that, in order to be able to create a national organization, they needed a separate organization.

— 392 —

Concerns with the splitting off of CIL programs

Landes: You've stated in previous interviews that you thought that that was a bad idea and were opposed to it. Why?

Heumann: I mean, I wouldn't say I was opposed to it because I—

Landes: We're talking "it" as the splitting—

Heumann: Separation.

Landes: Separation from CIL.

Heumann: Because I really felt and to some degree still feel that disabled people need a range of services, assistance; and there aren't that many of us, and from my perspective, when we broke all these organizations up, we also broke down the level of camaraderie that existed because you were setting up new groups that had to compete against each other for funding.

There certainly was that type of a problem that went on when the organization was one organization, where people felt like they weren't able to go after the money that they wanted to go after because, you know, management would say, "You can't go after this because we need to go after it for something else." So there were those types of conflicts.

But ultimately we went from one organization with one administrative staff and one administrative set of dollars to the Kids Project, CTP, DREDF, CIL—a minimum of four—and actually one could also argue the Kids Project—not the Kids Project, Through the Looking Glass, which was started by people who had worked at CIL—[Megan and Hal Kirshbaum]—so four to five organizations which developed and WID, which later developed. So six organizations. So six organizations that are all competing for similar dollars.

I guess my fantasy was that we would, from a management perspective, be able to get it together so that we could become an organization that could become multifaceted and could operate as one organization.

Landes: What legal services do you think disabled people in the Berkeley community were getting from DLRC that then they did not get from DREDF once it was formed?

Heumann: Well, DLRC was serving people locally. It didn't really—it was getting involved in national things, but its purpose was not national at that point, really. DREDF became more national and more state oriented, so its ability to provide local services—I mean, you always hear criticism about it. It's not necessarily appropriate criticism. You could only do what you could do.

But it was like the other day I was talking to some minority parents, who want some assistance in helping to organize a group of parents, primarily minority parents of kids with emotional disabilities, and they needed training on the IDEA, which is the Special Ed Law. I said, "I'll call DREDF." The woman said, "I can never get responses from them. They're never available."

Now, prior to that—and this is not a criticism; this is just—again, it's this difficulty of once you took away the legal arm from CIL—well, actually, you have seven or eight groups because then you have DRA [Disability Rights Advocates] which split off from DREDF—Sid Wolinsky's group, and Larry Paradise. They were split off from DREDF.

So I think that, you know, we gained and lost. But I think overall I would say that the concept of a national legal defense fund is very important, so the purpose of what people were trying to do, I think, is an appropriate purpose. I think the issue for me was could we not have an organization that did both national and local work? For me, I looked at CIL as a laboratory. That was always the way I envisioned CIL.

Landes: So that was really your vision of CIL, as a laboratory.

Heumann: Well, yes, because really it was an incubator, a laboratory. For me, it was the ability to get together with some very dynamic individuals who really felt like—we didn't come planning any of this. It wasn't that we set out in an organized way to begin to create this organization. I think for me, at least, what I began to see was that many of the thoughts that I had were shared by others, that when we were able to put those thoughts together and get funding for it, we were able to assist people to do what we knew we were able to do.

We were assisting ourselves as much as other people, as we were moving forward with our activities. So we were doing both empowerment of disabled people because that was a lot of what you saw in Berkeley in the 1970s, was a large group of people who felt an ownership for the organization, whether or not they were a board or in a paid position. I think people derived benefit from the activities of the organization, whether it was accessible transportation, or getting the IHSS that you needed, or being able to get a job, or getting curb cuts, or whatever it was.

The organization—you remember—it was always busy. There were always people coming. I don't see that now. I think something changed when the organization become more traditional in a certain way.

I think the other issue for me around the breakup was even at CTP—when I was involved with CTP, there was, I think and I may be very wrong—but there was a stronger push on IL as an important part of what was going on in the program. It wasn't just a training program for jobs. There was also the history of the movement and the value of—it was part of a different picture. Now it's an effective job development program, but there's no real sense of it being a part of a movement, I don't think.

Landes: I think that's accurate.

Heumann: So to me it was, like—you know, you wanted people to continue to feel that they were a part of a movement, even if they were just an individual coming in for something, that they played a role in a bigger picture. So if you looked at things, like thinking about Proposition 13—now, I haven't been involved at that level with CIL for so long, but at that point—you know, we were able to pull out fifty to a hundred people to go to council meetings, county board meetings, meetings in Sacramento. We could get van-loads of people to go up and deal with issues. From what I hear, you can't really do that.

On a certain level, you should be able to do it more now, not less. Now, it also could mean lots of other things, that more people have benefited. They're out, they're working, they're doing different things—but I think one of the big losses with all of the groups setting up is that there isn't a cohesive body of people who really have a vision together. They have organizational vision, but they don't have movement. They may have organizational movement vision, but we didn't—I mean, the Ed Roberts Campus, to me, is interesting because it's people coming back together again to be in one location.

While at CIL at one point, I remember having a discussion with Martin Paley, at that time the director of the San Francisco Foundation. CIL was centralized in one place so we had talked about expanding it so that we would be able to have mini-offices in different parts of Berkeley and Oakland, because it was difficult for people to get to one place—if for no other reason than to do intake and some basic assistance.

I think if you look at the problems that a person has, they would present themselves first at a place like a CIL because they would just come. Somebody would come to talk about what they needed, and they needed to talk to somebody who was not only willing to listen but could also be a problem solver with them. And the disabled people, the poor people and others, were that. They were problem solvers. They solved problems for themselves, and they were helping people solve their own problems.

But then what they were able to do in a broader mechanism like a CIL was to help people go get different resources. They didn't have to go someplace else to do it. They didn't have to make another phone call to another organization to learn about the culture of that organization. I think even if you look at the kinds of people that we served at that time, I think we were really beginning to serve a much more significantly disabled population of people. We were beginning to serve people who had mental retardation and psychiatric disabilities. I think it was in part, again because of the energy that people had together—this is obviously my interpretation, but people believed that you could make a difference.

At the same time, there were a lot of pressures within the organization because of the funding problems and because, you know, as the organization got older, people were not as idealistic. They wanted to be paid for their work, they wanted to be paid on time for their work, they wanted to be paid an appropriate wage for their work. They weren't like the beginning people, who worked basically for nothing.

Landes: Well, they were moving from their twenties into their thirties and beginning families, perhaps.

Heumann: Exactly. I think, again, those comments aren't meant as criticisms; it's the reality of exactly that. I really did feel that when that strike moved forward that, while it wasn't just nondisabled people who were involved in it, you never saw—I remember people saying to me, "You would never see this happening in a black organization," blah-blah-blah.

More thoughts on DLRC becoming DREDF

Landes: Let me finish up with the decision about the DLRC becoming DREDF, and then let's talk about the strike. How was the decision made? You mentioned some of the people, but ultimately at what point was the decision made, and who were the most important people on the pro and con side?

Heumann: We never really got into a very big con side. I think it was Bob [Funk] and Mary Lou [Breslin] and Pat[ricia] Wright who were very much involved in the development. I think Arlene [Mayerson] was probably not as much in on the conceptualization. Certainly, Bob kept Phil involved and myself. But it became kind of a foregone conclusion that this was what was going to happen.

Landes: And you certainly were the one with probably more reservations than others.

Heumann: Right, right.

Landes: So how did you feel when that decision was made?

Heumann: I felt conflicted because I did recognize the need for this national voice, which I thought was very important. But I did feel that there was a way of us looking at doing it without splitting things off. I felt then like I feel now, that we gained things and we lost things. Maybe Sid Wolinsky's program—and I don't know enough about it—but his maybe has become more the local advocacy legal arm. I think they probably do more general local legal representation. I may be wrong on that, but that's my sense of it.

[tape interruption]

Landes: You said you had your office over either in the DLRC office or very close to it.

Heumann: It was right there.

Landes: Did you continue to work out of DREDF?

Heumann: No, no, no, no, no. No. You know, I don't remember some of these fine details. I don't remember—

Landes: Let me ask it this way: What was your relationship to DREDF and its work once it was formed?

Heumann: What I try to remember is when it fiscally became a separate entity, because it was in '80 or '81.

Landes: So you're saying it was incorporated in '79 but that—

Heumann: I'm not sure. It was incorporated in '79, '80, yes. Have you talked to Bob at all?

Landes: No.

Heumann: Is somebody going to talk to Bob?

Landes: We hope so.

Heumann: And Mary Lou has got all this stuff.

Landes: I can check, so let's not worry about the dates. I'm more interested in your relationship.

Heumann: Yes. I think I was on the advisory committee. They had a national conference. I was involved with that. There was a time when there was kind of friction that was developing—growing pains of organizations splitting and people taking on different responsibilities.

[Tape 28, Side A]

Landes: We were talking about the split as DREDF became an independent nonprofit.

Heumann: You know, I think what DREDF has been able to do over the years has been very important in really establishing itself as a national legal defense organization for disabled individuals. I guess some of the conflicts, I think, that existed were in part because you had a number of neophyte groups that were evolving in the middle of the development of a movement. I think some of the conflicts which resulted as the organizations were splitting, I think, affected friendships also.

Landes: Were some of your friendships affected?

Heumann: Oh, yes. This stuff isn't all public, so yes, I definitely think there were times—there were bad times between DREDF and other people, yes.

Landes: Is there any of that that you'd like to talk about?

Heumann: No, I'm thinking. It's not that I'm avoiding it at the moment.

Landes: Tension over their having become an independent organization?

Heumann: There was tension over not being able to work well together. I left CIL in '81, and so I think some of the tensions then—you know, WID [World Institute on Disability] established itself in '82, '83, and they were just [pauses]—God, I really have to think about this. My first recollection, like, getting into thinking about different specific events, was there were a lot of painful times where people were not effectively working and talking together.

Landes: Was this true for you in your working relationships?

Heumann: Yes.

Landes: Would you speak about that?

Heumann: That's what I'm trying to ineffectively speak about. I'm trying to remember if it was around fund-raising or—I just remember that we were having a difficult time communicating in general. Bob Funk left in the eighties because he came back to D.C.,

and he went to work for the Republicans. I'm trying to remember when he left. He left a good number of years ago, because he first worked at Rehab and OSERS [Office of Special Education and Rehabilitation Services], and then he went and worked for EEOC [Equal Employment Opportunity Commission].

Landes: But I'm most interested right now in the period immediately after the—

Heumann: No, '79, '80—in that time period, no, I think there was just, like, for me, the tensions of change. I had issues with change. But I think in the very beginning it was, as I said, a foregone conclusion that these changes were going to happen. I feel like I was not able to effectively argue my position, and there were a lot of people who disagreed with me, then agreed with me.

Landes: Then also, when it became an independent nonprofit, they weren't reporting to you as they were as deputy director.

Heumann: Right, but you know, that [pauses]—I'm trying to think when they moved out.

Landes: When they moved out of the building across the street from CIL?

Heumann: Right, and moved down to San Pablo. They've been there the whole time, I think, right?

Landes: They've been on two different locations on San Pablo.

Heumann: Okay. I don't remember that as being an issue, the reporting, no.

Landes: Did you still have your office over across the street from CIL, or did you move—

Heumann: Well, it was CIL. CIL had many offices, if you remember. When I left CIL, I believe I was still across the street.

Landes: So you were certainly in close proximity to the people at DREDF in their very early months or possibly a year, before they moved to San Pablo.

Heumann: Yes. As I said, I don't remember when the split became final. Do you remember that?

Observations on some key persons at DREDF

Landes: No, I don't know. But we can determine that.

Heumann: Yes. Because, you know, I'm friends with people like Arlene and Julie [Landau] and Diane Lipton and those people, and I always maintained a good relationship with them, so we always worked together. It was kind of like a blending of things.

Landes: Let's talk about some of those people. Do you have anything that you'd like to say about your working relationship or the value of the work that people like Arlene was doing, for example?

504 trainings, 1978-1981

Heumann: Oh, you know, Arlene and Diane Lipton and Julie Landau and Mary Lou were doing very, very good work. I mean, Mary Lou's work with the 504 contract was great. That project in and of itself, I think, really was an incredible organizing tool because there were hundreds of people that were trained through that program. And I think the model that she had worked on developing was a very effective one because it really gave people some very good skills when they left those trainings.

Landes: Was she the key person in conceptualizing that training? Or was that done with a group of people?

Heumann: I think there was involvement of a number of people.

Landes: Were you involved?

Heumann: I believe I was involved in that contract, yes.

Landes: Do you remember who else?

Heumann: Bob, Mary Lou, Pat.

Landes: I'm speaking of how those trainings were conceptualized as leading to more involvement and advocacy on the part of people that went to those trainings.

Heumann: We designed the model for the training. The money came out from the Department of Education. The first round of jobs. The next round it came out from EEOC. But—God, when you sit down and try to think of all these fine details—I was involved in doing training. I was one of the trainers, I believe, for some of the 504 programs. There were a group of people who worked on it. Kitty Cone I think was involved.

Landes: When you say "the model," can you describe that model?

Heumann: I believe people were brought together for five days after going through a selection process. We competed for the contract, and we were given the contract. I'm trying to remember if we had one or two regions that we got the funding for. But we hired people who were then trained as trainers, and people, as I said, would come for a week.

They would talk about the substance of 504 and then also learned negotiating skills. Once you learned the substance of the law, you had to know how in fact to make the knowledge that you had learned usable so that you could actually go back into the community and deal with both preventing complaints from having to be filed, but then also dealing with complaints when they did need to be filed.

So I think the training materials were great. The trainers were great. Marian Blackwell Stratton was involved. [Alan] Kal Kalmanoff was involved. I think he was hired as the prime trainer, actually. What I want is a group of us to sit down and talk about this and remember all these things.

The CIL strike of 1981

Landes: Want to talk about the strike now?

Heumann: Oh, God. I don't know. Okay.

Landes: You've mentioned the strike earlier today, and it was also in previous interviews. In your mind, what's your understanding of the issues and the cause of the strike?

Heumann: I think the issues around the strike were money.

Landes: What do you mean by money? People not being paid on time?

Heumann: I think that was very substantially it. Things really did get to a very difficult time, when payroll wasn't being met and when we were trying to work out which people could go without their salaries until we got money. I think even at one point there were layoffs. I think things really got to a point where there was this conflict between management and some of the workers who believed that the way they'd get these issues resolved would be by going on strike.

Landes: Now, were disabled people involved in the strike itself?

Heumann: There were some disabled people who were involved.

Landes: Was it your perception that it was primarily nondisabled people?

Heumann: It was led primarily by nondisabled people.

Landes: Who all do you remember being involved in that?

Heumann: The people that stand out in my memory the most, of course, were, like, Doug Brown and Gene Turitz.

Landes: From the van shop?

Heumann: In the van shop, yes. God! At that point, CIL was about two hundred staff.

Landes: That late?

Heumann: Yes, yes, a hundred and fifty to two hundred. I know who wasn't involved in it. There were people, you know, from the community who weren't even that involved with CIL anymore who were coming back. I think it was a very stressful time for people. What role did you play in that?

Landes: I wasn't working there at the time. Then I got a call, but I didn't play any role in it.

Heumann: Yes. I think it was very hard on Phil. It was very hard on me, that we weren't able to resolve these problems. A couple of years earlier, I think, we had looked at the issue of unionizing workers, and I think we had gone through that process. I think it was decided—I think there actually was a vote that was taken as to whether or not to unionize. I think the vote came out not to unionize the organization.

Landes: The impetus for that union drive was probably the same issues.

Heumann: Yes. I mean, it was an undercurrent of what was going on within the organization.

Landes: How was the strike resolved?

Heumann: You know, I dread this discussion because I don't remember all these details, and I know that I should.

Landes: We'll ask somebody else.

Heumann: I'm trying to think who you'll ask. Anita Baldwin. There was a negotiating committee that was put together, and I think Anita Baldwin—has anybody interviewed Anita?

Landes: I'm not sure.

Heumann: Anita and Marilyn [Thornton] would be very important people to talk to. Marilyn was brought on as the comptroller, and then Anita was the director of services. Anita and Marilyn played a very strong role—we had an attorney who had come in. God! What's his name? [Ornstein].

Landes: Ornstein, you said?

Heumann: I think that's his name. But Marilyn and Anita—

Landes: Were key people in the negotiating committee?

Heumann: Yes.

Landes: So you were not—

Heumann: [Himma] Ornstein.

Landes: But were you involved in that negotiating committee?

Heumann: I didn't participate in the negotiating committee. I think they would come back to fill in myself and talk with us on issues, but we weren't involved in the negotiating committee. And the board, of course, was very involved. Jack Rowan was.

Landes: Who was involved in the negotiating committee on the other side, the strikers' side?

Heumann: I believe Gene and Doug, and I don't remember who else. Beverly woman? Someone who was—[whispers to herself] I think her name was Beverly. I don't remember. [normal voice] I think we brought in—oh, Ron Dellums' office was involved.

Landes: As a way of trying to resolve—negotiating and resolving the issues?

Heumann: I believe so, yes. Lee I think was involved.

Landes: Lee Halderman?

Heumann: I think so.

Impact of strike on CIL: changes on the board of directors

Landes: You've spoken a lot about the pain that the strike caused you and others. Do you think it in the long run harmed the organization?

Heumann: Personally? Yes, I do.

Landes: Why?

Heumann: [pauses] I think it allowed a more conservative, less visionary group of people to come in and take over the organization. I remember talking to Jack Rowan one day when we were in the middle of the strike. He was the chair of the board at that point. I remember him saying that he would be very comfortable if the organization had something like twenty to thirty staff, that he felt that that would be a manageable organization and the organization could live up to its commitments. I remember saying to him, "An organization of that size will never be able to do what this organization has been able to do."

People who had worked together, been friends together, were on different sides of issues now, and I think that caused tensions. I also think it put a damper on the organization's willingness to be creative. I think what happened was I left. I went to work for the state. I left pretty soon after the strike was over. I got on the board, but I got on the board only because of a little coup that Howie Harp had organized because what the board at that time was trying to do was to hire a nondisabled person to be the director of CIL.

Landes: You referred to that, I think, an interview or so ago. So Howie Harp and others—

Heumann: Howie Harp organized to increase membership.

Landes: Which could then vote.

Heumann: Which elected me to the board, and I can't remember who else. It might have been Margaret Jackobson. But at any rate, it got rid of—I think Jack Rowan was not elected to be on the board, and I don't know who else—Linda Thoms might have also been put off the board. That's how we got Michael Winter as the director, because they weren't going to interview Michael for the directorship. They weren't even going to interview him.

Landes: So the new—

Heumann: The new board—Margaret Jackobson, as I recall, became the chairperson of the interviewing committee, and then Michael was interviewed and selected. I think Michael did a very good job. Michael had reasonably good management skills and good fiscal

skills, and the one thing you can say about what happened with him is that they didn't have any fiscal problems. You know, of course, so many of the issues had been kind of like an erupting boil. You know, it had been expunged from the organization.

Landes: We're talking about the financial issues. Were there any other issues that were boils?

Heumann: Well, the management issue, I think was an overall issue, around management: personnel issues—

Landes: So you're feeling—

Heumann: The organization downsized dramatically.

Landes: Was this before or after Michael became director?

Heumann: After. I mean, much of this happened before.

Landes: So Michael was forced to oversee the downsizing of CIL.

Heumann: I think a lot of the downsizing had actually happened before Michael came on. I think Marilyn Thornton was forced to see the downsizing. Marilyn and Anita were the ones who—

Landes: What role was Anita playing at CIL?

Heumann: Anita was the director of services, and Marilyn—did Marilyn then become the director of CIL? She was the interim director, I believe.

Landes: I believe at one point.

Heumann: Yes. So I think, you know, Phil—

[tape interruption]

Phil Draper's important role at CIL

Heumann: You know, for me what happened to Phil was very sad because he, in my mind, had been one of the most influential parts of the development of CIL, even before I got involved. I think he was already involved in '70, '71. He always was a more under-spoken, understated person.

Landes: Yes, you spoke very eloquently about that in previous interviews.

Heumann: I think that his ending in the organization—I think it's very sad.

Michael Winter as CIL Director

Landes: The strike was the end of Phil's job?

Heumann: It certainly had a very significant influence in it because Marilyn was the interim director, and then Michael was hired as the director, so Phil basically was leaving at that time. I also think he was sick at that time. I think there was something going on medically with him. But I think there were all these divisions because there were people who were Phil's friends that caused all these antagonisms with the different groups within the organization. I think that there was a sense that there were people who were trying to make things better, and others who weren't really trying to make things better.

Obviously, everybody would have their own side, and everybody would feel like they were trying to make things better. Everybody would—I think people felt as though they were pushed into the positions that they were pushed into because problems weren't being resolved.

But I think the bottom line—in relationship to your question, I do think it had an effect on the organization. I've always felt it was really good that Michael came in as the next director, as opposed to what the organization was looking for. That particular board was really looking for a nondisabled person who they felt could be a good manager, and they didn't feel that the original vision of the organization—

I mean, if CIL would have hired a nondisabled director, it would have had the most profoundly negative effect on the country because CIL was at that point very much seen as the lead organization, and where CIL went, other people went, other organizations went. There was such a strong ideological belief on the part of some of us that the CIL should never be run by a nondisabled person. While it was true that there were fewer disabled individuals who had a combination of political and management skills, you could set up a team with a disabled person as the director; and if you couldn't find a disabled person who had that level of management skills, you could find a nondisabled person who would not be the spokesperson for the organization. So I think that was one of the real concerns with the people who were then in charge of the board.

Landes: What strengths did Michael bring to CIL as the executive director?

Heumann: Well, he had worked at CIL for a number of years because he had done an internship. I had met him in the seventies at the White House Conference on Handicapped Individuals. He was getting his master's degree in rehab counseling at the University of Illinois, and he came out to do an internship with us. So he really knew a lot about the community. He had a lot of friends there, and he knew about the organization.

Then he had left to become the director of the Hawaii Center for Independent Living. So he had actually run a center that I believe—

Landes: Before he came back to CIL?

Heumann: Exactly. So he had actually had management experience in running an independent living center. He had a very strong vision of the role that disabled people needed to play in independent living. I think he had a very strong commitment to diversity, very.

Landes: You've spoken that he was one of the elite people in pushing for more—

Heumann: I think at that point he played a lesser of a role, when he was there in the seventies, but he was involved with it. But he definitely had that very strong vision for diversity within the organization. I think his personal experiences—you know, having grown up in the south side of Chicago and his sisters and brothers were biracial—he had a whole different perspective of issues, both personally and professionally. Eventually he got married to Atsuko. His issues were not just around racial diversity; he was also very strong on cross-disability.

So really it was under him that some of the programs began to take more shape. I think the homeless project—of course, that's another project that split off. That was later on, under Michael. They split off.

So there are a couple of ways to look at it. My fantasy that everyone can work and play well together and you can work out these problems. The other reality of what has happened here in Berkeley is that you have some very strong, powerful, dynamic organizations that were influenced by CIL in its infancy—even people like Michael Daniels, who's the director of the homeless project in Berkeley. Michael came to CIL because Loni Hancock called me one day when she was—have I said this already?

Landes: Yes, you've mentioned it. Go ahead.

Heumann: Loni had called and said, I've got this VISTA worker, and I don't know—he'd been through at least two placements, and would we take him. That to me was the kind of organization that CIL was. We interviewed Michael and felt very much like he was a very hardworking person. He was a reasonably independent person, which was also something that we were—you know, it was that fine line that you had to play. You had to be independent enough to be able to run what you were doing, but team-oriented enough that you didn't go off on your own. But you knew when to come back and talk, and when to raise issues.

You know, that's not a lot of people. You know, people are either on their own or not on their own. So Michael Daniels came in as a housing specialist who really, over the course of the last twenty-one or twenty-two years, has done amazing stuff.

Michael Winter very much supported Michael in the development of the homeless project.

[Tape 28, Side B]

Landes: We're talking about Michael Daniels and Michael Winter.

Heumann: Right. I wasn't at CIL when some of these things began to evolve, but Michael Winter and Michael Daniels [worked] very effectively together. Michael Daniels and I worked very effectively together, because he was a thorough person, and you could see why he wouldn't get along in certain organizations because he was an independent guy. He also was outspoken, so he told you what he thought. If you didn't hear what he had to say, well, that could be a problem. But if you didn't take what he had to say as negative but rather as constructive, that was good.

I mean, I think about a lot of projects. Vicky Lewis ran *The Independent*, this great publication that has never been re-created. Ken Okuno and Vicky—I mean, I think *The Independent* had been started earlier, but we got Vicky as a VISTA worker. We had a whole bunch of VISTA workers. Vicky just did amazing work with that publication. *The Independent* was known all over the United States because it was a very creative publication. It wasn't a local, community-based organization. Its messages were national and, for that matter, international. The message was national and international.

I loved working with her because there was this energy that we were able to feed off of, and she was able to go off on her own and do work with other people. Now, everybody was being impacted by the physical problems. That was always an ongoing issue of having many more ideas than we were able to actualize because we didn't have the money for it.

Importance of CIL nationally: innovation and leadership

Heumann: But for me, when CIL was in its heyday, we did incredible things. I think there are a very few other programs—I think the center in Chicago, Access Living, which was one of the original ten centers that came out of the rehabilitation dollars in 1978, '79—and they actually started in a rehab center and then were spun off as a separate nonprofit. They are one of the few other centers that I think have ever really gotten to a level of where the Berkeley center was. They have survived long at that level of energy, which I think is very positive.

Landes: Who are some of the people you know who are involved there?

Heumann: Margaret Bristol is the executive director, and she's great. She's very good. They very much were helped by the fact that they came out of this rehab center, which had a very wealthy board. CIL started as a grassroots organization. They started as a grassroots organization, but that was part of a well-established nonprofit hospital.

Landes: They have a much more direct line to philanthropy.

Heumann: Oh, absolutely. They've been able to maintain that over the years. Plus they had a very strong vision of what independent living was all about, the kinds of changes that they believe need to occur, so they were able to combine vision and money. Now, they're not rolling in dollars, but they've been able to get both federal and state and private and foundation dollars. Jorge, my husband, visited there a couple of weeks ago. Came back talking about the center in a way that I used to talk about CIL.

But I think what—again, for me, the breadth of what CIL was—the van shop, the wheelchair shop I think are two examples. The job development program. CIL—not only was it the first independent living center, but until recently it was really the only independent living center, with few exceptions, that was doing work in the area of employment.

Job development

Landes: They were doing that from—

Heumann: The beginning.

Landes: The very beginning? When you came?

Heumann: When I came on paid staff, which was December or January, December of '73, January of '74, they had a job developer on staff.

Landes: Do you remember who?

Heumann: Oh, God. Yes, Deborah Meehan. Then we were able to get the CETA grant and Ann Steiner became the head. We had ten staff at that time. We built it up to ten staff. Joe Quinn was hired, and Joe is a dynamic guy. You know, you could really see things that we were able to do then—we involved DLRC and the job development program. We had everything there, so when we would go out and do training for employers, we also gave them training on the law as well as training on recruitment and accommodation. We did a whole range of things at once, and it was more natural. Things fell together more naturally because we were within a one-square-block radius.

Peer counseling

Heumann: I mean, even looking at the peer counseling work that we did—when we got the drug money—this was before that—you know, at one point we had peer counseling training where we were working with parents and kids. Jack Rowan was a peer counselor, working with some disabled youth, while Zona [Roberts] was working with parents. There were things that were going on that I don't know if they're going on anywhere now.

They were blips in time, but they were important blips in time because I think—

Landes: That was all your dream and vision, of what an independent living center should be, is providing all this range of services.

Heumann: But to me it was more than the services. What I felt was that we were in part trying to influence what other organizations were doing, and where other organizations weren't doing it, we at least for a period of time would have responsibility for doing it.

I remember when we got that grant on substance abuse, there were two things we did with the substance abuse grant. One is we were working with hospitals and nonprofits in the Bay Area to get them to make their facilities accessible, and at the same time, we were doing peer counseling with Steven Diaz and Randy Hepner as recovering—was Steven?—no Steven wasn't—

Landes: Randy and I came—

Heumann: Randy and you. Steven later on. Yes, it was the two of you.

Landes: Steven may have been earlier.

Heumann: Steven I think might have still had his problem at that point. But at any rate, yes, it was you and Randy that ran that project?

Landes: No, Hal [Kirshbaum]—

Heumann: Hal was the director of counseling.

Landes: Randy Hepner and I were the two people hired as substance abuse counselors.

Heumann: Yes. But, I mean, even if you think about how this little peer counseling program started and how it developed into a pretty large part of the organization, where we had someone like a Hal in charge. We had people who had all different types of skills, and we had the outside people who were coming in, providing us with more training, technical assistance for our staff.

The guy—remember?—from the county. There was a disabled guy, like a Ph.D. He was either a psychiatrist or a Ph.D. psychologist who would come in on a regular, like, monthly basis to meet with the peer counselors.

Then we had that college program—you know—what the heck was it? You know the one I'm talking about? That Pat Wright and Laurie Hill ran? The Antioch program. But I think for me, it wasn't for CIL just to become this service organization. It was really that.

Landes: Because advocacy was always a very strong—

Heumann: Advocacy and policy and personal empowerment. That to me—the services were a means to an end.

Landes: The end was the empowerment of the individual?

Heumann: Of individual persons.

Landes: And changing policies.

Heumann: And changing the communities. For me, it was because I had—you know, when I lived in New York and then when I came out here, we had been much more political than what was going on here at that time. We had been more cutting edge, I think, in certain ways.

But what existed here was this melding of services and advocacy and policy, which was very powerful, which we didn't have in New York.

To me, it was like a light bulb going on. As I've said a lot, we agreed with each other. I mean, that was what was very exciting. If we would have had the ability to have a management consultant or a strong manager on staff who had the same vision and the ability to deal with the fiscal problems that got out of control, I'm curious to see what in fact would have happened. We might have gotten larger then smaller because I think, you know, the issue of conglomerates getting bigger and then breaking up again is just what has happened over time.

But there were other things we were looking at doing. We were attempting to get into businesses. I mean, we did look at—

Wheelchair repair and van shop

Landes: And this is while you were there?

Heumann: Oh, yes, definitely.

Landes: What were examples?

Heumann: Well, what was going on with the wheelchair repair shop and the van shop. I mean, those were definitely programs that were looked at as making money, but again, there you had people who were running those programs who were a combination of—they were very community committed. I could have lots of feelings about what some of those people were involved in doing with the strike, but I do believe that they believed you had to provide a quality service, that they in fact worked very well with people, and they were very individually oriented to try to really help people get what they needed.

But we were very much plagued by the Medi-Cal billing systems, and this problem with having to deal without the economic resources. Now, very few organizations have gone into doing what CIL was doing. I think in part it's because—though there are more organizations that spun off because if you think that after the van shop ended, then eventually Bill started—

Landes: Bill Fryckman?

Heumann: Yes. The wheelchair repair program. When did Andy's program start, Wheelchairs of Berkeley?

Landes: Well, Andy left CIL. Worked at another shop.

Heumann: That's right, but Andy came from CIL.

Landes: Then he opened Wheelchairs of Berkeley, later.

Heumann: Right. But Andy did train at CIL. So all of those things, when you really think about the number of organizations, both for-profit and not-for-profit, that were directly and indirectly influenced by CIL, it's very significant.

Landes: Now, had there been thought given to other businesses that didn't come to fruition?

Heumann: We had looked at a point in trying to make money off of providing technical assistance to centers that were trying to establish themselves, both in California and outside of California. We had done some of that. We were doing some billing for those kinds of services. Bruce, Bruce—Bruce, the dancer. Ah! I'll think of his last name. He still lives here. Long hair.

Landes: Bruce Curtis.

Heumann: Thank you. Nicaragua. He knew Nicaragua. But, I mean, we were beginning to do international work. So we were looking at a technical assistance program as being one that could generate dollars.

Also ideas that we never really moved forward on—but I was laughing about it a couple of months ago because I met a woman who is now doing what I thought about. I was interested in looking at contracting with corporations in the Bay Area where we would provide them with services, so if a person on the job had a disability and they needed wheelchair repair or they needed support services or whatever it would be, to the extent that we were able to provide it, they would contract—we would be paid for providing those services.

But what I thought was the bigger market—because there weren't that many disabled people working in the companies—was nondisabled people who were working in the companies who would have a kid who became disabled or would have a mother or father who became disabled, and it was becoming a negative for the person working because they were having to take care of these issues.

Well, now there are in fact businesses that are being set up to do just that. I met a woman in Oregon. She works for a national corporation, and they are in fact going in and working with companies to do exactly what we had thought a little bit about.

So some of the things we thought about were, I think for most of us who have more significant disabilities—they probably were not ideas that people hadn't thought about because it was really, for me at least, things that I would problem solve about myself and problem solve what I thought other people could benefit from.

Then you'd sit down at a party or something and talk to somebody about an idea and, yes, they either had a similar idea and were interested in talking about it, or hadn't but they were still interested in talking about it, so it was—well, we got the substance abuse money. That in and of itself was great because we decided that we were going to go beyond getting funding from just the agencies that typically had funded disability. The substance abuse office had never funded anything on disability. The minority youth program that we had gotten had never funded anything on disability.

The women's economic agenda project had never funded—the [train whistle] program in D.C. had never funded anything on disability. But you had people like Corbett and others, and Cece Weeks and people who were getting involved in the women's movement—myself and Kitty and others—and we got involved to go to a women's conference. You talk to somebody at the women's conference about the need for something, and someone was in a policy position; they had money; oh, yes, it's a good idea.

That's the way some of these things happened. It was like we were beginning to network at a higher level than we had before. When we were able to network at a higher level, we were beginning to talk to people who had an interest in diversity, saw disability as a part of what they were trying to do, and had money to help deal with some of those things.

So the money at the wheelchair repair shop, to design a new wheelchair—I mean, that was very much, I think—you know, Herb Leibowitz and Phil Draper and a couple of people—Tom Fussy, probably, and others—who—Herb. Has anybody talked to Herb?

Landes: [no audible response]

Heumann: Oh, God, somebody should talk to Herb, really. Because Herb worked for RSA, the regional office, when the regional office was much bigger. Herb was one of the original supporters of CIL and helped get the center technical assistance on accounting and was involved really a lot for many years. His perspective would be very important because he was also very good friends with Ed and with Joan and with Zona.

And Martin Paley. Has anybody talked to Martin?

Landes: I don't think so.

Heumann: Martin would be another important person.

Landes: Who is Martin?

Heumann: Martin was the executive director of the San Francisco Foundation. He, I believe, was the first foundation to give money to CIL. He was a very strong advocate for CIL over the years. He now is on the WID board, but he definitely got involved in disability-related activity. Martin and Herb getting older. Herb's probably eighty. I think Herb really—if there's a real interest in capturing some of that.

Someone should talk to Sharon, Phil's wife. I mean, it's not Phil, but, you know, I think it would be valuable. I think as this crisis began to evolve—

Landes: You're speaking now, again, of the financial crisis?

Heumann: Right, the strike and the resolution of the strike and all that. Yes, Sharon certainly would know at least her perspective of what Phil was feeling. But I know it was very hard for him.

Mary Lester. Has she been talked to?

Landes: Yes.

We've been talking about CIL all day and at least in two, maybe three previous interviews, and we're really now talking about the tail end of your direct involvement as a staff member.

Heumann: There are so many other things—

More reflections on working at CIL

Landes: Any other reflections on CIL?

Heumann: Well, you know, I think about the time that CTP was being told by the fire department that they had to move. Did we talk about this?

Landes: No.

Heumann: That was great.

Landes: Talk about it.

Heumann: [laughs] The fire department decided that CTP had to move out of Vista College from whatever floor it was on.

Landes: Because it was on the fourth floor.

Heumann: Because it was on the fourth floor. We organized this huge campaign. We killed 'em! I mean [laughs], we basically—that to me, and those kinds of incidents—we had meetings with the fire department, where we basically said that we thought [that the] message they were trying to deliver would result in disabled people not being able to live or work above the first floor of anyplace, and that what we had to do was set up a mechanism to help people get in and out of buildings. But it wasn't [to] restrict our ability to move.

They were viewing a disaster in a way that said the only people who would not be able to get out of a building were those people who entered the building with a disability, but that we knew that if there really was a disaster, that there would be a lot of people who would be in that same situation.

Then there was a meeting at City Hall. There must have been a hundred people there.

Landes: So beyond you, who were key people involved in that?

Heumann: Phil was involved. Neil [Jacobson] and Scott [Leubking]. I don't remember.

Landes: I mean, let's remember CIL was at one time on the second, third or fourth floor—

Heumann: Of a building on University Avenue.

Landes: Yes.

— 412 —

Heumann: Also on Haste Street it wasn't on the first floor. It was above. But, you know, we lobbied the city council. But those types of experiences for me really showed that when you could really both effectively argue a point and pull together the community to advocate on issues that there was a lot that we could do.

Landes: I take it from some of your remarks that you feel that that is not the case now, at least to the degree that it was at that time. Is that a fair—

Heumann: I don't know how to answer it. I think there are different times now, so had everything stayed the same, we still may not have been able to do that. I don't know the answer to that. But I do know that there was definitely a level of activism that at that point in time helped to make some very important gains.

The transit issues. I mean, the work that Kitty and Hale and Karen did on transportation was phenomenal. I mean, some of the litigation that they were able to get Legal Aid to do that resulted in court orders prohibiting a transit district from going ahead and purchasing buses. So that was all very cutting-edge stuff that wasn't really happening anyplace else. Not that other things like that have not happened in other communities since then, and most people would not attribute much of any of it to that period of time.

But I think for many people who were watching what was going on at CIL and certainly during that period of time, from '73 until '81 or so, people watched CIL very carefully. You could just tell because when the International Year of Disabled People happened, the media attention that CIL got, from all over the world—Canada, England, Japan—it was doing, at that time, something that was unique.

Now things are less unique, in a good way because it's happening so many more places, and I think that's very positive, and I think CIL played a very strong role—Ed's vision in the beginning, when he became the director of Rehab, his risk taking to take money that he was being told he couldn't take, the ten centers in California, was a very critical part of all this. We did begin to create a number of programs that were able in their own communities to have an effect that did bring attention throughout the state.

I think when you look at the 504 demonstrations and when you look at the way the governor responded and the mayor responded and the Secretary of Health, people basically agreed with what we were doing. They probably wouldn't have allowed an equivalent group of nondisabled people to do the same thing. Someone could argue about was there a paternalistic aspect to what was happening, but nonetheless, I think people agreed with the need for change, and they supported it.

Landes: There had been strong organizing to get people to that position.

Heumann: Yes, you're absolutely right. But, you know, the takeover of that building one could never argue had been well organized.

Landes: No, I meant the organizing in the previous years that allowed public [phone rings] officials to respond in the way they did.

Heumann: Absolutely, absolutely. I mean [phone rings] it was a combination—

[tape interruption]

Heumann: Anyway, I think the annals of history—I think it's important to get the views of some of these other people because they were from outside the community, and to get an understanding of what they remember, what drew them and drove them to try to help CIL become more established, and what their perceptions were of the problems, and what they maybe would have tried to have done that we did or didn't listen to.

[tape interruption]

Landes: You talked about some of your highlights, and it sounded like the most exciting piece and parts of CIL were being able to mobilize community for particular end, to change policy. Any others that you haven't talked about that you'd like to just mention before we stop.

Heumann: Yes, the work we did around peer counseling, to me, in the very beginning was very exciting because—and what we did in transportation.

Landes: In terms of transportation policy, not services.

Heumann: Yes. I did talk about that, moving us away from doing services into policy.

But on peer counseling, in the beginning, we were not very organized. We were getting more people who were coming into the organization for services. There wasn't any real centralized way of providing services to people. There were a number of issues that were coming up. Who should be a peer counselor? Did a peer counselor need to have a college degree in order to be a peer counselor? I personally felt the answer was no, that a peer counselor needed to be able to demonstrate issues in their lives and how they had resolved those issues and the ability to listen and work and help people make changes in their own lives.

As the organization was getting bigger and we were getting people who had more significant needs, then you could really see the beauty and ability of bringing people in who had different levels of experience. What I always felt was important was never to cut somebody out of being able to do work in the organization because they didn't have a degree if a degree wasn't necessary.

Again, for a time there was a very effective triaging that went on in peer counseling. I think [it is something] that people like Ann Cupolo and Valerie [Vivona] and Hal should feel very proud about because there were some very good things that were happening, both for individual people and the ability to work with others.

I think an area that we were trying to get more involved with and had a lot of difficulty was within the developmental disabilities community. We were very much trying to serve individuals who had cognitive disabilities but were viewed as outsiders by the parents and professionals. We had disabilities, but they didn't trust us, and I think we were considered to be—they didn't know what to do with a CIL kind of concept, which was talking about empowerment.

Now you've got the self-advocacy movement of individuals with cognitive disabilities themselves, and CIL did and other independent living centers did play a role in this.

XVII. Building Cross-Disability Coalitions, Establishing WID, and Appointment as Assistant Secretary of Education

Early experiences with people with different disabilities

[Interview 17: June 21, 2001] [Tape 29, Side A]

Landes: Judy, in our last interview, we were summing up and getting reflections about your time at CIL. I wanted to go back earlier to look at some of where your ideas regarding cross-disability coalition building and developing political organizations come from. How did you come to an understanding of building a cross-disability coalition?

Heumann: When I first started going to school, I went to school with kids who had different types of disabilities.

Landes: In the New York public schools?

Heumann: Right. When I started to go to elementary school, I was in classes with kids with cerebral palsy. Some of those kids also had mental retardation. I really didn't know disabled people until I started to go to school, except I would see kids once in a while when I went to the doctor. My physiatrist was in a private office, I didn't go to a clinic. When I started going to school, except for the three months when I stayed at Rusk Institute when I was four years old, there were people with physical disabilities. Outside of that, when I was nine and started going to school, and then when I started going to camp, I went to school and camp with kids who had different types of disabilities.

So my experiential base was working with people who had similar problems from what I had, and different problems to what I had. I began to realize when I was in elementary school that there was a lower expectation for some of the kids in my class. That was very apparent because the school we went to had special classes in a regular school building. In the regular school, the kids stopped at the end of the sixth grade. There were disable children in my class who were up to twenty-one years old. I really started thinking very early on, that there was something wrong with this picture. I was lucky that my mother worked with other parents. I didn't stay in that school and I left at the eighth grade, which

was two years after the nondisabled kids, to go on to high school. But there were still people there who were older than I was who stayed in this elementary school.

Landes: Did the fact that your mother was involved with other parents lead you to see the importance of getting parents involved? Because part of this whole coalition that I'm beginning to refer to included parents.

Heumann: Yes, let me get back to that. When I went to camp, I went to two different camps. Both camps had disabled children only in them. The second camp that I went to also had deaf kids in it. So I started learning sign language from some of my camper friends.

Landes: At what age?

Heumann: I think I went to Camp Jened probably at thirteen or fourteen. At Camp Oakhurst, which was the earlier camp I went to, there were some blind people there, who had cognitive disabilities. That experience for me at Camp Jened also brought in a whole new disability group for me. I learned a number of things. One, the three women who were in the same bunk as I was, started to teach me sign language. The speech therapist said that I shouldn't learn to speak sign language because it would adversely affect their ability to learn how to speak. It was becoming very clear to me that if I didn't learn some sign language, we couldn't communicate. Because they couldn't read my lips and I couldn't necessarily understand their speech.

So I think that over the course of the years between nine and fifteen, my whole exposure was to people with different types of disabilities and people with different intellectual abilities. And again, this kind of overlay of seeing that people had different expectations for people who had disabilities other than physical disabilities. They were lower expectations. On a one-to-one level for myself, with my peers and friends, I didn't understand why they were being devalued more than those of us with just physical disabilities. I think your question is a good question because I've never exactly thought about this issue of what I learned from my parents as far as the importance of sharing.

I do feel that my parents, and in particular my mother, were good role models for me. My mother was very much a networker. She realized that what happened to kids in wheelchairs—that you didn't go on to high school—you went to home instruction. She started working with other parents, so she didn't do it by herself, and she didn't do it just for me. The goal really was to work with other parents to try to deal with the problem of getting schools open for disabled kids.

Landes: Was there a formal organization?

Heumann: No, they did it under the PTA of the school. So, my mother was the president of the PTA, not of the regular school but in the special classes. When she died we found this charm, which was a present that the parents had given my mother for the work that she had done. It was really something that I learned. My parents never said that I shouldn't be friendly with some of the kids. There was never any kind of message to me that I was better than the kids who had other types of disabilities. The work that my mother and other mothers were doing were really based on trying to get better education for all the kids. I didn't think about it in the beginning. It was just what I knew. I knew that those of us who had physical disabilities for whatever reason had problems with architectural barriers. I learned about sheltered workshops because of the kids that I knew in elementary school. What happened to the kids after they were twenty-one and could no longer be in the school? They had aged out.

Landes: Were these developmentally disabled people?

Heumann: Yes. They went on to sheltered workshops. That's when I started learning more about sheltered workshops, from some of those people who were my friends. Then in high school, the kids who had developmental disabilities, not just those who had developmental disabilities, people in those days would send you to a sheltered workshop if they thought that you couldn't go to college. There were some really crazy stories from friends. People who had cerebral palsy who eventually went on to college, but were sent to a sheltered workshop to do things like stuff envelopes, when they couldn't use their hands. A friend of mine was a post-polio quadriplegic, who couldn't use her hands at all, had also been sent to a sheltered workshop for an evaluation. For me, in addition to learning from my environment and learning from my mother and the support that my father gave my mother, and the acceptance that my parents had of all of these kids—. They were my friends, part of our network of people. My mother would talk about how she felt that some of the parents had low expectations for their kids, and they needed to do more work with their kids to help them progress more. There wasn't this low expectation for anybody, which I think was helpful.

Landes: Later, people have talked about a certain hierarchy among the disabled community. It sounds like what you are saying is that from the beginning, you saw through that and saw that in one way or another all disabled people were—.

Heumann: Adversely affected by disability. Not by the disability, but by people's views of that disability. The issue of hierarchy. When you were in elementary school that word didn't come up. But there definitely was a hierarchy when we dealt with nondisabled people. For example, the classes I went to were only with disabled kids. But once a week we would go to assembly with the nondisabled kids. They would select some of the good fifth and sixth grade kids who would take us to assembly and back from assembly. They would also come down to our classroom sometimes during the week to help us get our coats off. It was clear there that the nondisabled kids were more likely to help those of us who had less significant disabilities.

One of my first boyfriends was a guy from the regular sixth grade class. I knew on some level that it was going on. I felt badly about that. On the other hand, it was my way of making some contact with these other kids. They would come and we would clean the erasers. It was more likely that they would ask me or my friend Frieda, who didn't have a speech disability, to do those types of things. The hierarchy issue was something that I felt early on.

Concept for Disabled in Action: advocacy rather than independent living

Landes: When did you form the DIA? The DIA started in 1970. What was your conception of the DIA?

Heumann: One of the reasons that we started DIA was because I had gone to meetings with some other kinds of organizations. What I was experiencing before DIA was that there were different organizations that had been started to work on single issues. I was participating in a group that was working on architectural barrier problems. I just always felt that it wasn't, that I couldn't just work in an organization that dealt with one issue. When I looked at the problems that we were dealing with, they were multiple issues. I guess that fact, coupled with the fact that I knew I had personal interest in dealing with more than just access.

The reason we started DIA was because of the lawsuit that I filed against the board of education. When I was denied my teaching job, I started getting letters and phone calls from people. People would stop me on the street and say, "We're glad you're doing this." They may have had a sister, a brother, a cousin or a friend, who were experiencing all kinds of problems. When I decided to sue the board of education, I had a friend who got the *New York Times* to write a piece. Then there was an editorial in the *Times*, and I began to do some television and radio interviews.

The way that I had decided that I would talk to media, based on talking to other friends of mine with disabilities, was that I didn't want this to be seen as an issue that affected one person.

I didn't want it to be something that allowed people to think that the only problem we had was employment based. Rather to talk about the myriad of problems that disabled people were facing, so that people would get a more honest understanding of the problem. We decided that we would try to set up—. Do you know when DIA started?

Landes: I assume it was covered earlier in the interview. Here I'm much more interested in the original conception and how this idea of cross-disability coalition building fed into the mission of DIA.

Heumann: DIA from the beginning had people with different types of disabilities. We wanted it to be people with different types of disabilities. We wanted it to be an organization that was looking at system reform, and system reform that didn't deal with one or a few issues.

Landes: So you really saw it as a political organization that would push for policy changes and changes in law.

Heumann: I think, in the beginning, it was not something that well planned out. This was a bunch of young people and none of us had lots of experience in any of the civil rights or antiwar groups. I participated in things, as did some of my friends, but we weren't in the middle of leadership of any of those groups. We were stumbling along. We decided we wanted to start an organization that was originally called "handicapped in action." Within a week, we had it changed to "disabled in action."

We wanted to set up an organization which could represent many different people on many different issues. We thought about the importance of it being a cross-disability organization, because we felt that on some level no person should be left behind. Even in resolving problems, in order to be able to understand both the extent of the problem and solutions to the problems, you had to have a better understanding of the diversity of people who were affected by the problems. For us, there never was a discussion about whether or not this should be an organization that was cross-disability or cross issue. It was really always something that we had decided from the very beginning. But in saying

that we saw ourselves as being cross-disability, we were still pretty physically disabled oriented. There were people who had cerebral palsy, muscular dystrophy, post-polio in that group. There were some people with cognitive disabilities, but they didn't really play that big a role in the organization. In about 1972, when Willowbrook was happening, there was a little article in the paper about an organizing meeting for people around Willowbrook.

Landes: I wanted to get into that later.

Heumann: That's how we got more involved into looking at the DD issues. We consciously decided to send somebody to that meeting. That group was a group that only focused on DD issues.

Landes: Did you have deaf people or blind people?

Heumann: There were blind people who came to the meetings. I can't remember if there were any deaf people who came to meetings. They weren't on the board. When we started organizing with others at the national level, we went to the deaf and blind groups.

Landes: How did the purpose of the DIA evolve over those early years. You said you didn't go into it consciously developing a political organization, but that somehow evolved.

Heumann: We didn't call it a political organization. We saw it as being political. We basically saw ourselves as a group of people that wanted to make changes. The changes that needed to be made were both legislative changes and empowerment, and one of the things we were trying to do was to get more and more disabled people involved. We wanted to let people in the organization define what the issues were. We had lots of committees, and they were developed because people within the organization felt that there were particular problems that they wanted to be worked on. For example, we had a sheltered workshop committee. Neil Jacobson was on that sheltered workshop committee. I think that at that point in time, there were no non-DD groups that were looking at sheltered workshop issues.

It's not that we necessarily had that much depth in what we were doing. On one hand, we had no money and lots of different working groups. People were working or going to school and volunteering their time. But it was very clear that the goal was system reform for all people. There was a committee that was dealing with the Jerry Lewis telethon. We were dealing with Jerry Lewis way before many other people were. There was a hunger strike that a couple of people from the organization participated in outside of the telethon. We looked, from a political perspective, that we needed to empower disabled people to express what the problems were and to look for appropriate solutions. We worked with other organizations that existed within the city, but we were definitely the more militant of the groups.

Landes: Other disabled organizations, such as whom?

Heumann: Eastern Paralyzed Veterans of America had a group. Joe somebody or other worked on access work. Eunice Fiorito, I think both of them have died now. But, Eunice was the head of the mayor's office on disability. We worked with them. We worked with a group in Queens called PRIDE, which Ann Cupolo was involved with. We felt, on a certain level, like kamikazes. We felt like we had nothing to lose in what we did, and that we had to make political change. We had to hold elected officials accountable, that disabled people had to be viewed as a constituency that they had a responsibility to work with. We testified at hearings, we had demonstrations outside the governor's office in New York City. We did many different things. We focused on architectural barrier removal, transit issues, employment, education—.

Landes: So clearly your focus was on advocacy rather than on independent living resources?

Heumann: Nobody knew about independent living at that point.

Landes: How did you learn about the concept of independent living?

Heumann: I was teaching in New York. You had to have a Master's degree after you were teaching for five years. So I had taken one graduate course while I was teaching, but I was going to Columbia and living in Brooklyn. It was very hard for me to get to that course. So I decided that I would teach for three years and then go to graduate school. Then I would have my Master's within five years. I had applied to Columbia school of social work and been accepted. Then I got a call one day from Ed Roberts, saying that there was a group in California called the Center for Independent Living. I had just heard about this because Dick Santos and Larry Biscamp had come to a demonstration that the DIA had helped organize in Washington D.C. That was the first time that I ever heard of the Center for Independent Living. Ed called and said we've got this new organization interested in advocacy and explained the organization. He asked if I was interested in coming out, getting a Master's in City and Regional Planning, and getting involved with this group.

Landes: So this was in 1972?

Heumann: 1973.

Landes: Had you heard about the Independent Living Center in Boston?

Heumann: No.

Landes: So you, and presumably the other people in DIA, had no idea about what was going on in Boston?

Heumann: No.

Involvement with Willowbrook

Landes: You mentioned earlier the Willowbrook de-institutionalization. How did you hear about that, and describe it a little bit. How did you get DIA involved in that?

Heumann: Well, there was an article in the newspaper saying that there was going to be a meeting of people who were involved with Willowbrook, and that it was an open meeting to the public. I think it was Bobbi Linn who actually went to the meeting. We wanted to learn more about what they were doing, because working with a population of people who were devalued and living in an institution—.

Landes: Describe, briefly, what Willowbrook was.

Heumann: It was called Willowbrook State School for the Mentally Retarded. It was a facility in Staten Island, New York, which housed thousands of disabled people. Primarily, but not exclusively, people with developmental disabilities. You had a very high percentage of people who had what was called mental retardation. They may have been physically disabled, non-ambulatory, ambulatory, some people may have been deaf or blind or low vision. They had physical disabilities plus cognitive disabilities. There was an expose, organized by two doctors in the hospital. One, whose name was Dr. Bill Bronston.

Bill was one of the people who organized this meeting that we read about in the newspaper. We went to the meeting, started to go to a number of the meetings again because it was cross-disability. The conditions were really deplorable, outside of the fact that it was a segregated environment, a ghetto for people. It also was very poorly staffed and very overcrowded. People were living in inhumane ways. The reporter, Geraldo Rivera, that's how he got his start. He was brought in by Bronston and this other doctor, basically unannounced. He came in and made footage of the conditions that people were living in.

Landes: I take it he was a TV reporter at the time, in New York.

Heumann: Yes, he was not a known person at that point. But the conditions were so bad that it was a big issue in the city, and in the state. It got amazing attention. So we started going to their meetings and getting involved in the work that they were doing. I went out and visited Willowbrook. I attended a good number of meetings of this other organization. They got involved with us, on work that we were also doing with DIA. We tried to help them out.

[Tape 29, Side B]

Landes: Please continue with what you were saying and DIA's involvement with Willowbrook.

Heumann: DIA got involved with Willowbrook to give support to the activities that were going on around de-institutionalization. You had asked me earlier about whether there were deaf or blind people involved. There definitely were some blind people, because now I remember Adrienne Asch, who is blind, was also involved. Adrienne came to some of these meetings with Willowbrook. We felt that it was important to be able to be in solidarity with these people. Bill Bronston was a Maoist—he gave me my little red book. [laughter] It was just a whole new group of people, that didn't really understand our issues. We were learning about the issues of people with significant cognitive disabilities.

Landes: These were people who were referred to at the time as mentally retarded?

Heumann: The people in their group were mainly parents—.

Landes: I meant the people at Willowbrook.

Heumann: Yes.

Landes: And you were working with the doctor, and other staff people?

Heumann: Yes, Malachy McCourt and his wife were involved because they have a kid who has cognitive disability. Richard Levy, who was an attorney in a progressive law firm, and that was a really great involvement for us. It really helped us to expand our knowledge about the scope of the problem. Again, it was a way for us to network and continue doing disability work.

Landes: How along were you involved with that process at Willowbrook?

Heumann: I left New York in the summer of '73, so I was involved with this group from '72 until I left.

Landes: So you feel it gave you and others in DIA a much better understanding of the problems faced by developmentally disabled people?

Heumann: Yes, but equally, I think, that what we learned through all this was that it was very important not to think of the haves and have-nots. There were different ways of working with people with different types of needs, but at the end of the day what we were trying to do—again, because there were no services going on and we never thought about services as a part of the work we were doing—what was going on was that we were expanding the base of people to work on issues that were cross-disability.

Early CIL versus DIA: services for adults versus advocacy for all

Landes: Let's now talk about your early involvement with CIL. You came out to Berkeley in 1973. You've developed over the years, both before your development of DIA, and it sounds like from very early on in school, working with people with other disabilities. As you got involved with DIA, and you became interested in legislating legal change. Did you find that perception or understanding at CIL when you arrived?

Heumann: CIL was, at that point, it was somewhat cross-disability. It did start out with people who were blind and had physical disabilities, and Hale was involved when I came out. But they didn't have any experience working on children's issues. They were mainly dealing with adult issues like social security, housing, and access issues. They weren't doing anything in education. They had Jan McEwan and Hale, they would have been the two people who had acquired their disabilities when they were young. The rest of the staff all had their disabilities when they were older. That impacted on their knowledge base of children's issues.

Landes: Talk a little about what differences your experience as a child with a disability going though the public schools from those of Ed [Roberts], who was a jock in San Mateo county until fourteen or fifteen, when he got polio, and was suddenly quadriplegic. Do

you see ways in which that impacted the perceptions of the two of you in terms of various issues relating to disability?

Heumann: Ed was on the board of CIL when I got there. But I think what I felt that I brought, and eventually when we brought more people on, was a whole new experience. I had no idea what it would have been like to grow up without a disability. They had no idea what it was like to grow up with a disability. So even in thinking about the kinds of changes that we were trying to create, they didn't think about children's issues very much. They didn't have a base of knowledge. They didn't understand anything about segregated schools, they didn't understand anything about denial of education, and they conceptually didn't understand how disability at a young age resulted in people not having the ability—. People who became disabled later on experienced being nondisabled. They knew what they had, and they knew what they lost when they acquired their disability.

Those of us who had our disabilities when we were younger, we never experienced having things that everybody else had. We were trying to create it, and figure out how to do it. At the end of the day, those of us who couldn't walk, couldn't use a bus, whether or not we became disable at twenty, thirty, or five, or at birth. I think because education is so important in helping people think about change and value themselves, many people who became disabled when they were younger were pretty devalued by their society and by their families. There were lower expectations. I think it helped CIL to be able to expand the base of people that we were looking to work with. It was really over the first three to five years that I started working with the center that we started talking about the issue of kids. We started struggling over the issue of parents, and did we want parents to be a part of the center. And if so, how?

Landes: You did or didn't?

Heumann: We did. Until '77 or '78, when we got the education money, there was a real debate about whether or not parents—. Mary Lou was one of the strongest people to oppose parents getting involved.

Landes: Let me go back a little bit, early on when you started to introduce these ideas around advocacy you had learned in New York, was the leadership and staff of CIL receptive?

Heumann: Yes, and I was part of that leadership. I think that what was going on at CIL at that time was that we were pretty much receptive to thinking and talking about anything. I was there from August or September until the following summer, and I was on the board then. When I came back on the staff, in December of '75, that's when we really, from a programmatic perspective, started addressing how we ran the organization, and what we needed to do to expand the work that we were doing to really be a more cross-disability organization. Children were one issue, but we were also bringing more people in who had more significant disabilities. They weren't just people with spinal injuries or just people with cerebral palsy or the blind, they were people who had more multiple disabilities, more complex issues.

My feeling about CIL, in the beginning, was that we were looking at the issues that were problems for us. Housing, transportation, benefits counseling, those were all the kinds of things that were problematic for one or more of us within the organization. When we brought more staff on that understood the issue of lifelong disability, I think that also

allowed us to think differently about how we would work with people who had different types of disabilities.

Landes: Was there any tension that evolved around those issues?

Heumann: I think the biggest tension at this point, in the eighties, there was a whole other set of tensions that came on when we started to look at bringing people on with psychiatric disabilities. In the seventies, there was some discussion about whether or not we could serve people with developmental disabilities. Not the Hale Zukas's of the world who were playing a leadership role within the organization, but people with cognitive disabilities. That's when we started to also serve deaf people, that was another whole issue. Should we be serving deaf people? We started getting involved in serving deaf people, in part, because there was a guy who was born deaf but later became a quadriplegic, Dale Dahl. Here you had somebody who couldn't go just to the deaf organizations, because they weren't accessible to him. He was now experiencing problems that dealt with both his deafness and his physical disability.

So when we started to look at doing deaf services, it was a big issue because there was a deaf group in the community, DCARA [Deaf Counseling, Advocacy, and Referral Agency]. There was resistance by DCARA to CIL providing services that they said they were providing. We put together a work group of deaf people to help us look at the needs of the deaf community and look at whether or not CIL should begin to provide services to the deaf community. There was some external hostility, and internally we were also trying to figure out if we could expand services to deaf people. What did it mean and were we going to be able to do it?

Similarly, we consciously decided that we wanted to start working more with the DD community, people who were in institutions, and people who had more significant disabilities. Each time we added a new group on, there was always some consternation and question. Should we be doing this? Are we overextending ourselves? Shouldn't we limit what we're doing? I was doing a lot of the program development, not exclusively, but a lot of it. To me, it always felt very important that if the center was going to be a cross-disability organization, we needed to bring in people who had those disabilities into the work that we were doing.

If I were to compare it with what went on at Willowbrook, for example. When DIA did work with the Willowbrook group, there were very few people with cognitive disabilities involved. It was much more a professional parent organization. When the center got involved with this, with trying to work with the DD community more qualitatively, we went to people who had developmental disabilities to get them to serve on the board, and to get them to help with services. We didn't go to the providers or parents, we went to the affected group.

Inclusion of parents of children with disabilities at CIL

Landes: You referred earlier to a debate about whether parents should be involved. How did that get resolved?

Heumann: What I remember is that we had discussions about the pros and cons of parents being involved. Mary Lou, the way she talks about it now, I think, it is a really good thing that we did. I think some of the questions that people had dealt with parents [were] over protectiveness. A concern on the part of some that parents wouldn't necessarily be respectful of us as disabled people in leadership positions. It was really kind of a throwback to what some people had experienced from parents who were not necessarily as proactive as some might have liked. And they were seen somewhat as part of the problem, not necessarily part of the solution.

I think the way we ultimately dealt with it, was that we felt that parents of disabled children could learn from us. If they could learn from us, they would be effective advocates for their children. If other parents could learn about the work that we were doing at CIL, it would also be helpful for them in beginning to see that their children could grow up and could become leaders in a community. With the parents, when we hired them, there was a committee of people. Of course, it was a committee that did the questioning and interviewing of parents. I think people felt really good once the process was finished that we had hired good parents, who were themselves activists. On some level, their activism was reinforced by the center.

Landes: Who were some of the parents that were hired?

Heumann: Diane Lipton, Pam Steneberg, Lynn Gray, and Beverly Bertaino. What I always found interesting about those parents was that the parents who applied for these jobs were parents who had kids with very significant disabilities. Yet they felt comfortable in looking at working within an organization where they would clearly be the minority and also having to learn and take directions from adults with disabilities. I think it went very well and their kids started meeting adults with disabilities, which is very important. In bringing on the parents, we added another level of living the dream, trying to create what we though needed to be created in order to help people become integrated members of their community.

Introducing New York's aggressiveness to Berkeley's CIL

Landes: You said earlier that in New York, you didn't have a concept of independent living, and that you were introduced to that once you moved out to Berkeley. What was your initial impression? Did you see ways that your work and advocacy could work hand in glove with the independent living movement?

Heumann: I had felt that DIA was a much more proactive advocacy organization. But, I felt that it was a real brilliant idea to get services as a part of the political work that was going on here. One of the problems that we always had in New York was getting people to the events. People couldn't get up, they couldn't get out of their house, they couldn't drive, there wasn't an accessible subway system. I felt when I came out here that having the advocacy joined to the services was great. To me, things like personal assistant services, something that I didn't have in New York. Someone helped me a few hours a day, but there wasn't any notion of a personal assistant services program. A lot of people didn't know about—.

— 426 —

Landes: It wasn't an entitlement of any sort.

Heumann: No. I think I was learning by being here, and I was also able to take my activism and integrate it into the work that was being done. I found Californians to be somewhat more passive than

New York people. Although, they had done some great stuff.

Landes: Describe that difference, between the New Yorkers and the Californians. In terms of the work that was involved with CIL, and the political work that was going on. How did that play itself out?

Heumann: I think that it was more a part of our being to attack. If there was a problem, you had to attack it, aggressively deal with it. I'll give you an example. The best way that I describe the importance of being somebody from New York. It happened in the eighties. I was using the bus, and the buses here were always breaking down. You passively sit, waiting for the next bus to come, pissed off and annoyed. Nobody did very much. I was waiting for a bus in New York, and I had called to see what time the accessible bus was going to be coming.

I had gotten there half an hour early. The first bus came by, it was wheelchair-accessible but it was crowded. When I went to get on, the driver said it was full. I said okay, and they told me to take the next bus. So I kept talking to my friend. Then the next bus came by, and it was also accessible, but they wouldn't let me on it either because they said it was too crowded. At this point I started thinking, why am I being so passive? Waiting for Godot. The next bus that came by was also crowded and the driver said there was nothing he could do. He was about to pull out, and I took my wheelchair and jammed it under the steps of the bus. We came to a meeting of the minds, and after about ten or fifteen minutes of the bus not being able to move because I had jammed myself underneath the steps of the bus, a cop came over and told the guy he had to get me on the bus.

I remember thinking that if I was in California, I never would have done that. There's a different way of doing things. I felt so good that I was able to deal with that problem. Maybe I'm generalizing, but to me, it was important, here at the center, to be very aggressive here in Berkeley. I also always thought it was important to be polite as long as you could be polite, and try to work with people. But urgency is something that, I think, I felt. The cross-disability step was something that some of us thought was more important than others.

A national perspective

Landes: So, in addition to the New York attitude and the emphasis on cross-disability coalition building, what else do you think you contributed in your early years to the CIL? What else did you introduce?

Heumann: I had just come back from Washington.

Landes: From having worked with Harrison Williams?

Heumann: Exactly. We were working with ACCD, and I had a much better understanding of how Washington worked. It was helpful because I was able to help look at certain sources of funding that we hadn't looked at before. I was able to help do broader networking than we were able to do before. We also became more diversified in our funding. As independent living was becoming something that was being discussed, because CIL had a Michigan program and a Boston program. There was a grant that CIL had gotten which was evaluating work that CIL was doing and evaluating peer counseling programs. I was able to help with dollars and contacts. And to help elevate IL to more of a national—.

Landes: So your work in Washington really gave you a national perspective and also gave you an education about how the political process worked in Washington.

Heumann: Right, and I had lots of East Coast contacts, and there were very few East Coast contacts in Berkeley at that time. We were also able to get the ideas of independent living more known within the disability communities.

Landes: You mentioned the Boston Independent Living Center, which I understand was formed at roughly the same time as CIL. But when you were in New York, you were not aware of that?

Heumann: No.

Landes: When did you become aware of the Boston Center?

Heumann: I think not until I was out here.

Landes: Was there much contact between CIL and the Boston center?

Heumann: We had some contact. Fred Fay was involved with the program at the time. Fred was a friend of mine and he was on the ACCD board of directors. I remember visiting the BCIL program. I think we felt that the Boston program was more conservative than the CIL program.

Landes: Was there any cross-fertilization of ideas?

Heumann: Yes, there was some work that went on between us and Michigan.

Landes: Detroit, Michigan, or somewhere else?

Heumann: It wasn't Detroit, it might have been Ann Arbor.

[Tape 30, Side A]

Landes: Judy, could you just reflect and sum up your contributions and impact on those early years of the CIL in Berkeley.

Heumann: I think I was influential in bringing people from New York out to the center in Berkeley. Word of mouth allowed people in New York to begin to look at the fact that a program like CIL could be beneficial in helping to advance political objectives. It was looking at the problems that disabled people were facing and trying to fill that gap. That connection

was something that we recognized was very important. Because I'm a networker, and I was doing a lot of national work, I was talking to people about CIL.

CIL was certainly getting a lot of exposure because of the work that Ed and Phil and others were doing. People who were interested in the research that was being done, Sue Stoddard for example, thought it was important. I think, for myself, knowing people and talking to people and encouraging CIL to be a place that people could come to visit to learn about independent living. We had lots of people who came from other parts of the country and eventually other parts of the world to learn about what we were doing. I think I was helpful in getting the organization that type of exposure, so that people came to Berkeley as one of the places that they wanted to learn more about.

I think I helped CIL, in the seventies, in really becoming a much bigger organization than they envisioned themselves. I really pushed hard at looking at and designing programs that would allow us to be more cross-disability. It was in the seventies that we brought deaf services in, started working with people with cognitive disabilities, dealt with de-institutionalization. One thing I was instrumental in is at one point the CIL had applied for a grant that would have allowed us to become a paratransit program. I was in Washington at a meeting when the board had voted on doing that. Phil had supported it. It was very hard for me because I loved Phil and I agreed with him on most everything. But I really disagreed with the idea of setting CIL up to do paratransit. I really felt that if we did that, we would become part of the problem, not part of the solution. We did a re-vote of the board and agreed that we would not be a paratransit program, but rather continue our focus on advocacy and litigation.

The truth of the matter is, it was better because of Betty McMuldren and myself getting a CETA grant to set up a paralegal program. I say help and hurt. On the one hand, CIL was being very stretched, all the new programs that we were starting were stretching the organization because we didn't necessarily have the management capability. We were always suffering under the fact that fiscally, the organization didn't have the infrastructure to deal with the money appropriately. I think those were some of the strains that were being put on the organization. On the other hand, I felt we had this unique opportunity. We had Ed in Sacramento, we had Brown as the governor, we had Carter as the President. There was a great receptivity, an ability to persuade funding sources to listen to the things that we wanted.

So the substance abuse program that we started at CIL was because of work that I had done. You never do anything by yourself. I'm not wanting to say that I did these things by myself. My feeling was that we needed to look at disability as something that shouldn't just be funded through the traditional disability oriented programs. We really needed to look at ways of getting money in to deal with cross-disability issues. Substance abuse was something that people didn't really think about as a disability, but we knew that it was a problem both to people who were substance abusers, but also to disabled people who were substance abusers. The work that I was involved with helped us begin to do more work on things like networking within the women's community, dealing with accessibility issues in the homeless and battered shelters. I helped bring on some good staff. We had an incredibly good group of people who were highly motivated, idealistic, and had strong vision and a commitment in people.

Because we had such a good group of people, people worked really hard. We wanted to succeed. I think we wanted to be able to prove that what people said about what we were or were not able to do was wrong. We were really predicated on advocacy. Everything that we did was advocacy oriented, self-empowerment oriented, getting more people to view themselves as able to contribute more and willing to participate in removing barriers. The work that we did with the city, the coalition work with the county, all of that was work that I was involved with and supported. On the other hand, maybe I was pushing too much. Retrospectively, I think that it is unfortunate that CIL broke up like it did.

We always had internal struggles going on. Different project managers felt that they weren't getting the attention or money they needed. The bottom line was that we were one organization and we had one goal. We looked at the needs of people across the board from one perspective. One of things that you hear people talk about over and over again in this community is personality differences and organizations not working collaboratively together. We didn't have those exact issues at that time, because we had internal problems, but we didn't have five or ten organizations that were all totally separate or distinct.

Landes: Any other reflections on your contributions to CIL?

Heumann: We did a lot of legislative work. I think that was important, that we were players at the state and national levels. One thing that I did was encourage our being big and broad, not limiting ourselves. And it happened you know. Vicky Lewis and the great work that she did, and the support that we gave to her through the *Independent*. Our work with VISTA volunteers, the job development program that was extended so that we had ten people doing job development and job placement. The paralegal program, which spun off to become DREDF. All of those programs, things could click together much more quickly. People could come in, you could identify their needs, you could help them go get peer support so that they could be stronger advocates and get housing.

At the same time, we were saying to people that you had an obligation to the organization. CIL was a very bustling place. People got involved with demonstrations with the city, they got involved with demonstrations at the county. They were involved in things in Sacramento. People believed that they could make a difference. That was something I feel I helped to contribute to. I was willing to travel, I may not have been in the organization as much as some might have said. But it was still networking, and getting our vision of what IL should be all about out there.

Special assistant to Ed Roberts at the California Department of Rehabilitation

Landes: In late 1982, you worked for about six months in Sacramento at the Department of Rehabilitation, where Ed was the director. Why did you go to work for the Department of Rehabilitation? What did you want to accomplish there?

Heumann: I think there were a couple things. One was that I felt that after the strikes, and Reagan, we were losing a lot of money. Jack Rowan had said to me one day that his vision of CIL was an organization of twenty or thirty people. When I heard him say that, I thought I can't be here. My vision isn't little and manageable, my vision is big. I can't feel comfortable working in a way that wouldn't allow my vision of what should be happening to happen. I felt that downward spiral, that I wouldn't be helpful. I had been talking to Ed about what was going on. He was able to get a spot for me to come up there and work in Sacramento. I didn't sit back and think, okay, now I want to do a job change, so I'll go to the State Department of Rehabilitation, which is the job of my dreams. It was more that I could work with Ed, I could work with Joan, and it was a state position so I could continue to do networking. It seemed to me to be a reasonable next stop. I had concerns working for the government, I had never done that before.

Landes: What issues did you work on there?

Heumann: I was working with the Rehabilitation Advisory Committee [RAC]. I did some legislative work with Ed. I did a variety of work with Ed and Joan. I think my primary area was the State Rehab Advisory Committee.

Landes: What was the role of that committee?

Heumann: It advised the state agency, it was gathering information on issues that were going on. It tried not only to get the Rehab agency to work better, but also to look at issues that other agencies needed to be working on.

Landes: Were these community people or people from within the department?

Heumann: No, RAC was community people.

Landes: So you were the department person working with them. It was a way of providing consumer input to the department?

Heumann: Right.

Landes: Describe that work a bit more.

Heumann: I got there in April or May, and we left in January. More of what I remember about what was going on there was that it was the end of an administration. I came up there trying to work hard, trying to work with RAC, learn about what was going on, meet with staff, and try to be as proactive as possible. What eventually became very clear was that the bureaucrats in the agency knew that the time of the administration was going to be coming to an end, that Brown couldn't run again. Even if a Democrat won, there was no guarantee that the people that were there would continue to be there. They stopped working. I remember talking to John [Hessler] one day and saying that I talk to people about assignments that need to be done, and I don't get them back. He told me what was going on.

Landes: So the bureaucrats saw you as having lame duck status?

Heumann: Yes, I think they saw all of us. So, for me, I learned a little bit about state government.

Landes: Were there any achievements with RAC?

Heumann: Nothing that strikes me.

Landes: So even though there was input coming from that committee, it meant a wall of resistance.

Heumann: Well, remember I was only there a short period of time. I think the RAC—. There's two questions. What role did I play in helping the RAC do much of anything? In a six month period of time, I don't think I made it reverse what it was doing. I think I supported its proactive activities, and I think I was supportive of Ed and Jim [Donald] and Joan. We would do work with Washington and with a slate of issues. I was working with Ed and Sid Wolinsky and Joan on a report called, "Trust Betrayed, Hope Denied." Oh, that was after I left the state agency.

Landes: Did you travel while you were at the Department of Rehabilitation?

Heumann: Yes, I did some traveling.

Landes: Where?

Heumann: I went to different parts of the state, I still went to D.C. I was on the board of the American Coalition of Citizens with Disabilities.

Landes: Did you go as a state employee or was this work outside?

Heumann: You know, it was one of these blurry things. Ed basically let me continue to do what I was doing. So I was a state employee continuing to do that work.

Landes: What else were you doing at the Department of Rehabilitation?

Heumann: I got on to the CIL board.

Landes: While you were working for the state?

Heumann: Yes, while I was working for the state. I had left CIL as a staff person. There was a little revolution. People who were on the board at that time were trying to hire a nondisabled person to be the director of the organization. The board felt that it was very important to get somebody in with good management skills. They were overlooking the fact that it could have been somebody with a disability and good management skills who could run the organization.

So Howie the Harp had contacted me to see if I would be willing to come onto the board. They were trying to get Jack Rowan unseated and get Michael Winter hired as the director. Margaret Jacobson was on the board. I had to get approval that it was going to be okay for me to run for the CIL board because I was working for the state. We got that approval from whomever, and I ran for the board and was elected to the board. Michael was hired as the executive director. I was doing work with the state IL coalition at the time. In '78 and '79, CIL had been very involved in getting the state to pass legislation for independent living standards for the state. We'd also been very involved with the work going on in Washington and getting federal legislation for the creation of independent living centers at the federal level. I was still involved with all that.

— 432 —

Landes: What else specifically did you do as an employee of the department?

Heumann: I was basically a community liaison. But I was a special assistant to Ed.

Landes: Which meant you could do anything?

Heumann: Anything he wanted me to do. The value of being a special assistant.

Landes: What were some of the highlights of that period?

Heumann: That time that I was there, the issue of being able to get involved with the board of CIL again was very important. I think it was very important to get Michael in, he was an important next step. Other highlights for me were learning more about state government, meeting and working more with some of the cross-disability groups that were part of the RAC. The RAC was representative of cross-disability organizations, as well as learning more about the state agencies in Sacramento.

Landes: Did you bring representatives from disabilities that had not previously been in RAC?

Heumann: No, I don't think I expanded it while I was there, it was a pretty big group. As I said, in any new job you spend three to six months learning the job, getting to know the people and how you're going to do what you going to do, and then it was over. We also started to work on WID while I was in Sacramento. So Ed and Joan and I had been talking about this organization, we had decided that when this part of our lives ended, we wanted to continue to work together. We talked about what we felt needed to be done next. We talked about a public policy institute, so we spent some of our time working on meeting together to discuss what the organization should look like, getting it a name. So when we left in January it was clear that we would set up the bylaws, and Joan, Ed, and I would be the founders of the organization.

Lessons from the state government and assessment of Roberts as Director of Rehab

Landes: Before we move on to talking about the World Institute of Disability, is there anything you'd like to say to sum up that period? You said you learned a lot about state government by working on the inside, were there other key things that you learned that were important in your later work at WID and in the Department of Education?

Heumann: Yes, I had learned from Ed that if there's something you really want to do, even if people tell you that you can't do it, you can figure out a way to make it happen. I think when Ed used federal money to set up the independent living centers, people talked about whether he should be using the dollars to do what he did, and he basically had a polite "screw-you" approach. He had a vision that he wanted and it helped me learn later on, when I went to work in a federal agency, that it was important to understand what you want. It's important to figure out a way to get what you want. I also think for me, working with the state allowed me to learn about the importance of government in playing a role in improving the quality of life for whomever.

But also, I learned more about who the progressive thinkers were and who the problem people were. The problem people were more those who didn't agree with the IL philosophy, harbored anger and resentment towards disabled people who were talking about the importance of a disability rights movement, and who viewed state government as an entity that needed to be forward thinking, supportive, progressive. You always had those people inside. I had to isolate those people that you didn't want to work with. You had to work with those people that you thought could be valuable.

Landes: How well were Ed's ideas received within the California Department of Rehabilitation?

Heumann: I think there were some people who to this day think what he did was great. There are other people that to this day think what he did was terrible.

Landes: What is your conception of what he did?

Heumann: I think that he did a lot of very good things. His very being challenged certain people's thinking about what their jobs were all about. His very being, being a significantly disabled individual who was now heading up this big agency, who had been ten years prior, told that the agency couldn't serve him because he had too significant a disability. Ed, too, was a very big networker. When he worked with the state agency, he really embraced cross-disability, and particularly really working on issues of people with cognitive disabilities. He brought Bill Bronston, and Bill who I knew from New York, was eventually hired by Ed to work in state government.

Ed worked with some of the best and brightest people in the DD community, and I think he was revered for that. He got along with diverse groups of people. He didn't feel above people with different types of disabilities. He saw himself as a role model, and to this day I meet people who had met Ed. Parents in particular, and other disabled people would talk about what a big difference he made in their lives. I think it was in part because people would look at him and wonder how this guy was even alive. Yet he was so vibrant and articulate, and allowed people to believe that they could do more and their kids could get more, whether they were disabled people themselves or other people. He continued to challenge people, because he was irreverent.

Landes: How were his ideas received by directors of the Departments of Rehabilitation in other states? Did he have a national impact at the state level?

Heumann: Ed was involved in the Council of State Administrators of Vocational Rehabilitation, CSAVR. They didn't exactly know what to do with him. Some of the state directors agreed with his positions, others didn't. He was always challenging people, and always pushing the envelope. It was like anything else, there were some people who thought he was a breath of fresh air and providing meaningful guidance and leadership, and other people that wished he went away. They thought he wasn't based in reality and was a California cuckoo. He also was well connected with legislators. One thing that was very important was that Ed being in Sacramento as long as he was, he got to know a lot of legislators. Both staff and legislative members had to deal with him. I think that helped some people change their views in some way about people who had disabilities. I think he was a trailblazer. He didn't pay as much attention to how things were happening, he left that up to other people. He was moving forward.

Landes: Did Ed or you think there were certain things that he had failed to do that he had really wanted to do while he was director? Did you ever discuss that with him?

Heumann: We certainly talked about things that needed to be done, work yet to do. I don't recall ever having a conversation about if he could do it over again, what would he do differently. He might have had a discussion like that with Joan, but I don't remember.

[Tape 30, Side B]

Establishing the World Institute on Disability, 1983; Three cofounders: Heumann, Ed Roberts, and Joan Leon

Landes: You mentioned previously how the germination for the idea for WID developed. Talk a little bit more about that. You, Ed, and Joan, while you were still at the Department of Rehabilitation, had this idea of a public advocacy institute.

Heumann: I think we were looking at next steps in our lives. We couldn't go back to doing what we were doing before. We had to look at moving forward to do new things. I think we were all committed to wanting to continue do work in the disability arena. As I have said, we were committed to working together. We understood our strengths and weaknesses, and felt that the three of us together were a good team of people.

Landes: Talk a little bit about what you saw as your respective strengths and weaknesses.

Heumann: For myself, my strengths were that I had experience as a teacher, which was very important for educational issues, my experiences at CIL, my experiences at the state, but equally important for me, my strengths are that, I think, I'm a visionary. I think I'm a strong networker. From a fund-raising perspective, I was interested and committed to looking at ways of raising money, convincing people that what we were trying to do was good, and trying to get a new organization started to fill a critical gap. Because it was becoming very clear that just like there had been a legal arm set up because there wasn't a voice to speak on behalf of disabled individuals on legal issues, whether it was legislation or direct representation, there wasn't really a body of people who were focusing on policy. When you look at other movements, public policy institutes were things that the women's community, the African

American community, also had been setting up. So, taking the skills that Ed, Joan, and I had and pulling them together to create this public policy group which would not only deal on specific issues, but also ultimately bring more disabled people into the arena of public policy. It would help get people trained on public policy issues so that we could play a different role.

One of the things that was becoming apparent at that time also was that we were moving from a movement where—. Our first priorities with the centers, while certainly policy-oriented, were trying to address immediate life-threatening issues for disabled people. Getting people the basic support that they needed, so that they could get out of their house and plan their life and move forward. When it came time to deal with the big issues, and for us we were looking nationally and internationally, we looked at things like personal assistance services and thought that California had a pretty good program.

But personal assistance service was a major issue around the country, and we think that if you look at the independent living centers and the movement, we were thinking what were some of the major public policy issues that needed to be addressed in order to allow the goals of independent living to really be accomplished across the country. I think that was one of our thinkings, which is why we selected issues like personal assistance services as one of the first activities we wanted to work on. Aging and disability was another issue that we, early on, started to work with because we had this approach of looking at constituencies that were not yet benefiting from the philosophy of independent living. Broadly enough, I think what we saw was that the aging community is not just a population of older people, but it's the providers of services, the people who were doing public policy on aging. If you looked at the number of disabled people in the country, the big numbers come in the aging population. Their model of service delivery was adversely affecting our ability to get what we felt we needed for the younger population. At the same time, we also believed that the elderly population was suffering the same way that the younger population had been suffering, by this paternalistic approach which looked at older people as sick and unable to do for themselves. Particularly people who were becoming disabled when they were older.

We were trying to look at areas that were critical to the advancement of the Independent Living movement that would allow us to move forward on this cross-disability agenda, would allow us to be working in new arenas with new groups of people, and to be looking at how to do systems change, with Washington as one of the big focal points. Although we continued to look at California as a laboratory. A place where there was great resources, I don't mean in money, but in terms of good work that was being done by many organizations and people.

The way I've dealt with my weaknesses over time is that I don't want to be the person who's managing the day-to-day operation of organizations. I certainly know what I believe a well run organization needs to be. I'm very into paying attention and working on setting up an organization like that. Being able to hire good people to do management. I could learn to do that, but it doesn't allow me to do bigger picture. Ed was less into management than I was, he was bigger picture than I was.

Landes: What do you mean by bigger? Internationally, or a broader concept of disability?

Heumann: No, I don't mean that at all. Ed was not inhibited in terms of going out and meeting new people. People that had nothing, on the face, to do with disability at all. We had different areas that we focused on. We had areas that we focused on together, and then we had areas that we—.

Landes: We'll talk about that momentarily, because I'd like to flesh that out. What were his particular areas of interests?

Heumann: Certainly public policy, personal assistance services, international—. In the beginning we had a series of discussions about whether or not we should be called WID. Should we call ourselves a World Institute? Should we be looking externally? Ed and I thought there was a lot for us to learn, about what was going on externally, and a lot that we wanted to share. Disability rights is a relatively small movement, and based on what he and I had learned over the years, through our international travels, people that we knew and had befriended, we felt that it was very important to be forthright and upfront in calling ourselves an international organization.

Some people said that funders wouldn't give us money if we called ourselves an international organization, but we felt like trying it. If it didn't work, we could change it. Ed definitely was into the aging issues. Ed brought things in like a program that we had started to do in the area of developmental disabilities. It was an organization that was basically running a training program in different states, originally focused on parents of developmentally disabled people. Then we expanded it to include disabled individuals themselves. It was called Partners in Policy. Ed got involved in things like greenlining, he got involved with people like Bob Gnaizda and Sid Wolinsky more than I did. Ed could deal with some of these guys that I had aversions to. I think one of the differences between Ed and me was that he was a man and I was a woman.

Reorganization: Heumann and Leon lose codirectorships at WID

Landes: Could you be a little more specific in how that played out in your respective roles at WID?

Heumann: There was this one really bad time at WID. We had started out as basically all being co-directors. Then there was a new guy brought on the board from the New York who felt it wasn't a good management structure, and that what we should do is have one director. Ed would be the director and Joan and I wouldn't be on the board and no longer be co-directors. Ed met with them, and basically agreed to allow this to happen.

Landes: So not only did you and Joan lose your codirectorships, but you were also taken off the board?

Heumann: No, we weren't. There was no fucking way I was going to allow that to happen.

Landes: So Ed agreed, but what happened?

Heumann: I can't remember all the details, but I remember that somebody called and said this was what was going on. I didn't know anything about it and Joan didn't know anything about it. My bottom line was that if I wasn't going to be on the board I was quitting the organization. I didn't agree with what was going on, taking us away from being co-directors, but I knew that at some point it was going to happen. But I remember I was really angry at Ed, and really angry at Joan because she was going to go along with it. I felt it was very disrespectful and very sexist. The truth was that the organization wouldn't have happened in the beginning if Joan and I hadn't worked on it as we did. Ed was in Sacramento, we were down here. We were doing the grant writing, we were doing the conceptualizing, we were out getting the money and the office and doing stuff to get the groups together. So, that didn't happen, we didn't get thrown off the board. But we were no longer co-directors.

Landes: How did those tensions get resolved? Or did they?

Heumann: I think they got resolved over time. I guess they got resolved by continuing to do our work. For me, it was a very, very hard time. I felt very betrayed by what had happened, and I talked to Ed about it.

Landes: What period was this? Was it early on?

Heumann: No, we started WID in '83. It was five or six years into the organization when this happened. About half-way through my being there, I think.

Joan Leon's contributions

Landes: What were Joan's strengths and weaknesses? What could she bring to the organization?

Heumann: Joan is an excellent writer. She has a lot of experience in fund-raising. She learned a lot over the years in CIL and in the State Department of Rehab about legislation. She understood a lot of the major issues that we were dealing with in CIL and at the state agency. She was very close with Ed. Ed and I knew each other since '73, but Ed and I had hardly ever worked together. We were really more friends until I worked for him at the state agency. When I left to go to Washington, Ed went to Sacramento. When I came back, I worked for the center, and Ed was in Sacramento.

So we actually never worked on a day-to-day basis at CIL. He was on the board, we did some board stuff together, but we never worked on a day-to-day basis. Joan had worked with Ed on a day-to-day basis since '72 or '73. So they had a very strong working relationship. She was, on some level, an extension of that. She had her own ideas and her own capabilities, but Ed had great trust in her. She had been with him through thick and thin at the state agency.

Landes: What were some of her own ideas?

Heumann: Joan was great on the public policy aspect. She understood what public policy was all about and she helped conceptualize some of things we had to do. She was good on research design, she was a good schmoozer, she had a lot of experience with fund-raising before she came to CIL. She had worked with the Tom Dooley Foundation. She just had a lot of strengths. She was a person who did not need to travel. She could be in the organization on a day-to-day basis, whereas Ed and I didn't envision ourselves as nine-to-five, five days a week, people in Berkeley.

Landes: So in a sense, she was a fund-raiser and administrator.

Heumann: And a grant writer, and a conceptualizer. We could sit down and talk, she remembered names, people, and places really well. She was an avid reader. She was able to help look at what else existed throughout the country and made sure that as we were designing work, we could be knowledgeable about what other things that were going on that could influence our thinking. Those were all very important things, and she was good on numbers. She was good on budget development, on oversight of the money of the organization, and she was able to work with some of the staff really well, because of those skills.

Focus on personal assistance and aging at WID

Landes: Once WID was formed, what issues or projects did you specifically get involved in?

Heumann: Personal assistance services, aging, international work—

Landes: So you were doing all of those simultaneously?

Heumann: Yes, because we were getting grants for hiring people. I was actually the program officer. We got a research and training center from NIDRR. We got two grants. The first grant we got from NIDRR was the international project.

Landes: What was that?

Heumann: The IDEA [Individuals with Disabilities Education Act] project, they still have it today. The first two grants that we got from the Department of Education, the international project and the research and training center on personal assistance—. I was the program officer for the research and training center on personal assistance services.

Landes: As program officer, you were the person at WID in charge of overseeing that research and training center?

Heumann: Yes, also I was in charge of what was going on in the international project. I was very involved in the aging project.

Landes: Were all of these projects early on? Or was this over a period of years?

Heumann: Yes, over a period of years. We started with the personal assistance project. Pretty early on, we started with the aging project, too. With the aging project, we had a project that we did jointly with UCSF [University of California, San Francisco]. We jointly got a grant from the Mott Foundation, and the purpose of that project was to convene a meeting, and a monograph would be developed to look at aging and disability issues from the IL perspective and from the perspective of the aging community. It was a really important project because [Dr.] Phil Lee was the chair of the board for WID.

Ed had grown up in California, and he knew many people from living here, and going to the university and his work. He was able to use many of those contacts as we were doing things like core development. He had worked with people like Sid and Bob Gnaizda earlier on, in the sixties and seventies. At that point the [University of California, Berkeley] Disabled Students' Program and others were working with Ralph Abascal. Ed knew these people, they were friends, and they were very helpful in various ways as we were working with WID. At any rate, the aging project was very helpful because it helped us to begin to make linkages into other established organizations. It helped us to meet with people who were actually receptive to listening to what we were talking about when we were talking about aging and disability, who were willing to look at the importance of the IL movement influencing how elderly and disabled people lived their lives, to get that community, many of whom were researchers and providers, to sit down face to face with disabled individuals of all ages, who were able to talk about the kinds of changes that we felt needed to go on.

Then we got a grant that Lillian Pastina ran, that was actually doing work with seniors who had disabilities. It was peer support work, helping them to learn about what their needs were and become more empowered.

Landes: You talked about working with other individuals and organizations that were involved with aging people—who were some of these people or organizations?

Heumann: The Villers Foundation, we worked with the House Committee on Aging, and we worked with people in the Senate. We worked with people from UCSF.

Landes: For example, who?

Heumann: Phil Lee, Carol Estes, Dorothy Rice, Ronnie Pollack from Washington D.C., AARP [American Association of Retired Persons], John Rather. The fact that we got money from the Mott Foundation, and that money was given so that we could hold that first conference at the Johnson Foundation building in Wisconsin, John was very helpful in a lot of that. John could take ideas that Ed and I had, and put them on paper and help move them forward. Great ideas without being able to do anything about them are a big farce.

Landes: What were the greatest successes in the work of the aging community?

Heumann: I think some of the good work we did in aging was getting able to speak to some of the most important people in the field of aging. Getting to know them, and having them getting to know us. To get them to start looking at things like nursing homes issues, in-house support services, de-institutionalization questions, the ability for people to hire and train their own workers, and empowerment issues. All of those things were very important. For us, it was to learn about how people were thinking in the aging community. We got involved with groups like OWL, the Older Women's League, we had gotten involved with Maggie Kuhn and the Gray Panthers. I got involved, and became a member of the board of the Over Sixties Health Center. I began lecturing on aging and disabilities.

Landes: Was that here in Berkeley?

Heumann: Yes, I was lecturing with Meredith Minkler, School of Public Health, on aging and disability. Meredith Minkler really focused a lot of her time on aging and disability. She looked carefully at the IL paradigm versus the traditional senior paradigm. I got involved in the American Society on Aging. I was doing panels at national conferences on aging. I think we were able to also learn from work at CIL. There was a percentage of the population that we served who were elderly. We, at one point, had gotten a grant from San Francisco Foundation that was specifically focused on working with blind and low-vision elderly people in Berkeley at the senior centers. Gerald [Baptiste] had run that project, but I had learned a lot from that project. It was another way of bringing another group under the umbrella of IL. But also to really focus on public policy issues. They were the hundred pound gorilla.

When Claude Pepper was looking at things like personal assistance services and consumer control, we were now able to participate in some more of those discussions. One of the things that we did in personal assistance services and aging was decide what we were trying to do. We were trying to define what we felt personal assistance services should be. Who should it cover? What are the different models for knowing how to use it? What were other states and countries doing? What were the different models out there? How were the programs impacting on people? It allowed us as we were moving forward with the agenda on personal assistance services, on national and states legislation consulting and helping them take the disability data we had been gathering and using it, and it helped us as we did conferences to bring together a cross-disability and cross-age group of people.

What we had started doing at the Berkeley center very much carried over at WID. You need to be as broad as possible, people shouldn't be excluded. You may have to look at how personal assistance services may vary, depending on the person and what the person wants. If a person is blind, it's a different sort of service than a person who is physically disabled. Someone who may need a facilitator may be different, but it allowed us to have much richer discussions.

[Tape 31, Side A]

Landes: We were talking about resistance, did you meet any resistance from within the organizations on aging?

Heumann: I think skepticism is more the word I would use than resistance. Many of the people that we dealt with were persuaded by things that we were saying. But when it came to applicability, they didn't have enough of a vision, necessarily, as we did. You did have people like Phil Lee, who was very revered in the policy arena. It was because of him that we were able to do much of the work that we did. He knew the people. He could bring them to the table and funders who were doing work in aging to see aging and disability as a viable topic. The little community that we worked with, the policy people, and some of the legislative people were helped by time. Time was helpful. People had time to learn. Then you also get very much involved with the big associations, like nursing homes. You buck up against the same things that you do for younger people. Who is driving people not getting services in their homes? It's the bigger companies that are making money off of getting people out of their homes and into these institutions.

Landes: I was speaking from within the organizations, rather than from—

Heumann: I think it's the paternalism. It's the same thing I discussed with the rehabilitation agencies. I didn't experience it as much when I was talking with the top leadership of these groups that we were working with in these groups. You would experience it more when you went to a conference and you would do a panel talking about aging and disability. People said this is something good for you because you're younger, what about these people who are older and can't make decisions and want to make decisions. They don't want to live at home anymore, they want to go someplace else, that's where you met a lot of the skepticism. Remember that the Bay area had always been pretty progressive as far as aging and disability. There had been strong coalitions between the elderly and disability communities for many, many years. In the sixties already, when there were the attacks on SSI and IHSS, there had been a coalition of aging and disability people. We had some of those connections. But I think at the end of the day, the problem has always been at some level people not knowing how to get to the next point. If you don't have the public policies in place, don't throw the baby out with the bath water. I don't recall feeling like there were groups that wouldn't talk to us, that completely poo-pooed what we were saying.

Landes: And that work continued throughout your time there?

Heumann: Yes, I don't know if they're doing it anymore. I'm sure they are doing some of it around personal assistance services, but I don't think the focus is there on aging and disabilities like it was before. Then the international component still does go on.

WID in the international arena

Landes: One of your interests at WID was the international arena. Speaking now of your time at WID, what was the early work you did in international work at WID?

Heumann: The work we were doing internationally at WID was continuing work that Ed and I had been doing prior to WID starting. The way we looked at our international work at WID was to learn from what other countries had been doing in areas we had been focusing on, to help us learn about different models and methods. One of the other premises of our work was that we had a lot to learn from what was going on in other countries. In many other countries, national health insurance, personal assistance services, and other types of economic support were in place.

We felt it was not only important for us to inform our world, but to inform disabled people and other policy makers about what was going on in other countries. It was really to look at what we could learn, and on some level it was also helping people in other countries learn about what we were doing. We had this stronger civil rights movement than in many other countries, but we had much weaker policy and social welfare issues. Personal assistance services was one of the major first things that we started with. We wanted to inform ourselves of what was going on in other countries. We knew people, like Adoph Ratzka, who had been working on personal assistance services already and doing a lot of thinking on that issue. Kalle Konkalla from Finland, who was involved both in independent living and personal assistance services. We used WID also as a training ground. We had people who came from other countries. On some level CIL had gone through this shift. It had downsized a lot, and Michael was there. Michael certainly had an international interest and a real focus on Japan. I had made contacts with people when I was at CIL from Germany and other countries, who were coming over and spending time at CIL. So there was now an interest in some disabled people coming over and spending time in the Bay Area, and we were helping some of those people also coordinate their schedules, and used WID as a base that they could learn from and help share information with us and go to CIL and other programs and learn about what was going on there.

Most significantly, the personal assistance services program recognized that we could benefit from learning more about what was going on in other countries with personal assistance services. Eventually, we moved on to going after this grant from NIDRR, which had previously been held by an organization in New York that was doing international exchange. The purpose of the grant was to provide money for people in the U.S. to go abroad and learn about work going on in other countries. We decided to go after that grant. We actually got Rehabilitation International involved with our IDEA grant. We basically beat out the grantee that had the money for a long time. It was so political that they gave two grants. They thought if they defunded this other program, there would be a problem.

International lessons on personal assistance services

Landes: Let's go back to what you were learning about your work with personal assistance. What do you think that you and others were learning from other countries?

Heumann: The Swedes were setting up a personal assistance services program which was more extensive than most of the programs we had here. It was a very innovative model, where they were able to get the county of Stockholm to turn over money to this new group called STIL. That enabled STIL to set up an organization that was a cooperative run by disabled people, and could provide many more hours of service, and allow people to get the support they needed outside the home. IHSS was, on the one hand, the largest program of personal assistance services around the country. But it was a restrictive program, you couldn't get more than seven some hours a day. Technically speaking, those hours were not to help you go to work, they were not to help you travel or go on vacation. They were hours that let you survive but didn't necessarily let you live, especially if you had more extensive needs. So we were learning about programs like the STIL programs.

We were learning about programs in Scandinavia that provided support to the parents, much more extensive personal assistance services support than we had here. We learned about models that were going on in Germany, and were going on in Finland, and in Canada and Japan. While they had more extensive programs, one of the issues that they were dealing with, as we were, was this belief that the reason why you couldn't go to a consumer-directed personal assistance services model was because you couldn't trust whether disabled people would know how to spend the money on personal assistance as opposed to frivolous things like drinking or gambling.

There were common issues in dealing with governments and trying to persuade governments to look at things differently. I think one of the things that was different was that our civil rights approach was different than what was going on in many of the other countries. There was more of an uphill struggle for the disability community to get its constituency to see that the support that they were getting from the government should be seen as support that helps them live their life. As opposed to supports that were there to buy them off from living their life. There was more of a complacency. Ed or I were being asked to go over and talk to people in other countries about the IL movement and its proactive positions. It all was a part of this PAS work that we were doing on some level.

The independent living model versus the paternalistic model

Landes: I take it you were talking about European countries as well as others. How did they receive these ideas, the IL model?

Heumann: Finland actually had created an IL program at the same time that the CIL was being started.

Landes: Was it consumer driven?

Heumann: Totally, except that we didn't know anything about each other. I had actually met the guy who set up the program in Finland before I met the people who set up the program in Berkeley. The guy was named Kalle Konkalla. Nothing is identical, but it was as identical as it could have been. Especially since nobody knew each other. Basically it was disabled people who got organized together to set up an organization of peer support that worked on personal assistance services. It was to become political and services, and it was in '72 or '73 when they set themselves up, and it was called Threshold, and it's still around. They were doing work with cross disabilities, cross age, working with the government. I think that the disabled people that we were meeting in other countries were not the leadership, but members and average persons. They were having difficulty grasping the American approach of confrontation. A lot of our movement really was confrontational.

Landes: The New York attitude.

Heumann: But even in California, more assertive, more aggressive. Trying to get people to understand what we were doing with 504, there was no ADA at that point. We had a civil rights movement here, but many of these other countries didn't. They had a women's movement, but they didn't have much of a civil rights movement because they were pretty much a homogeneous population of people at that point.

Landes: The United States as a nation, has a pride in individuality, much more so than probably European countries. Did that have any impact? Was it a problem of understanding this concept of individual rights as opposed to collective rights?

Heumann: I think the way I would put it is, I think the U.S. doesn't believe that there is a real role for government as an ongoing part of your life. The government should be there to step in for an emergency, it should not be obtrusive, it should be invisible, and there's no question about the government being involved. One of the reasons why we don't do national health insurance. There, people believe that the government plays a very important role in their lives. This was really one of the struggles, that the social welfare approach was one which was kind of an overpowering, controlling approach. So in getting assistance from the government, the government also played a very strong role in deciding how to take care of you. What we heard from the leadership was, the issue that needed to be dealt with, was allowing people to take control of their own lives.

Landes: When you say the leadership, you're talking about people like Adoph Ratzka—

Heumann: —and Kalle. Peer support was a very fundamental part of the work that they were doing. The Finns were doing peer support around the same time that we were. It was the same concept. Over the course of the years, Lillian Pastina, myself, and Ed were being brought over to Europe to do training on peer support and independent living. We were in Japan doing work on civil rights issues, independent living, and personal assistance services.

Certainly, as we got into doing more international work and began to do work with people from Latin America, the concept of independent living was somewhat challenged, the terminology of independent living. Germans don't use the word independent living, they use another word. This independent living being seen as individual as opposed to being connected to others, that was something that we began to hear people talk about. I think in Europe, the issue from a disability perspective—. I'm not talking about ecology. If you talk about ecology, they would say that our individuality is what is causing so many of the environmental problems. We don't look at ourselves as being part of the world, we think we're better than everyone else. When you look at issues of the military and war, that's where you could get into the heavy political and ideological discussions of U.S. policy versus European policy.

On the IL level, the leadership felt it was important that the members have opportunities to learn about how we had identified problems, created solutions, and challenged authority. That was a big thing that they were trying to do, to get people to recognize that challenging authority was important. If you didn't challenge authority figures, you couldn't solve problems that they were identifying. The problems were very similar. People were complaining about personal assistance services where they didn't have enough control, where they weren't selecting their hours, where they didn't get to select their own people, where other people made decisions, where they weren't doing their own training, where they would live in housing developments and have to share personal assistance so it restricted their ability to get up when they wanted to get up and go to bed when they wanted to go to bed. Adolf is from Germany. He did his undergraduate and graduate work at UCLA, and then went to Sweden. He is this meld of German, U.S., and Swedish politics. That was a very big issue. We would come over there, and there were struggles going on. Not only with the social welfare staff in county government—

Landes: You're talking about Stockholm now.

Heumann: In Sweden, but also in other countries. Things were being done, the government was providing, but the government was controlling.

Landes: It was more an paternalistic model.

Heumann: Right. When I first learned about what was going on, and I started learning about it in '72 or '73, that was also something that really helped inform the work that I was doing. That was the first time I went over to Europe and saw national health insurance.

Landes: Where did you go?

Heumann: I went to Heidelburg and to Stockholm.

Landes: Was that to a conference?

Heumann: I went to Heidlelburg for the wheelchair para-olympic games with my brother and two of my friends. When I was there, it was the first time I had ever been out of the country. I wasn't an athlete, I had been going to meetings at a place in New York City called the Bulova Watch School, which trained disabled people to make watches. They also had wheelchair basketball. There were the wheelchair games, and they had a big group of people going over, so we went. While they were doing sports, and I was watching, I was also getting to meet people and talking to people.

When I was talking to people, I would ask questions. What is it like living in your country? Do you have any kind of economic support? It was also the same time that I was learning about what was going on with the disabled veterans of the United States. I learned that if you were a veteran, you got a benefit based on the level of disability. But if you were a civilian with the exact same disability, you didn't get that benefit. I was learning about that at the same time I was learning about what was going on in other countries. People were complaining about the fact that they weren't getting enough in these other countries.

I was laughing about the fact that they could complain about not getting enough when we had nothing. I had no personal assistance services. There was no money that we could get to renovate our houses or apartments. At that point, there was very little support from the government in funding disability organizations. That was going on in these countries years before us. In '72 and '73, it was very important for me to see that there were other ways of doing things than what we were doing here. Over the course of the period between my first visit out of the country and WID, I had been learning more, talking more with people, and learning about the strengths and weaknesses of what was going on in other countries and here. My philosophy was, and is, that there is not a country yet that exists that combines a civil rights approach and also provides the social welfare supports to allow people to live a life of equality. Somehow there has been this either/or scenario. Either the government provides and you have no real rights to be involved in how things are being done, or you don't get anything except in an emergency situation and you have this aspiration of civil rights and equality which is isn't attainable for people who have disabilities that limit their ability to do certain things. That was what we were talking about, thinking about, and it was involved in the way we were doing our work.

We learned about programs for the elderly, which were going on in many parts of Europe. In England, which was in many ways more progressive than what we had because there were services in the house. You still may have had this heavy overlay of "we know what's best for you," but at the end of the day people were able to stay in their homes more and not go into institutions. That was true in Sweden and other countries, too. It was an opportunity to share ideas, to learn from each other in a way that we couldn't learn in school. There wasn't an opportunity to learn about these things in the U.S. Nondisabled people have so little understanding of how other governments work and the kind of supports that people get in those countries. People in those countries believe those supports are important, and believe that their taxes should pay for those supports, in order for them to live a life of equality.

Landes: You were going internationally to observe these other models. Presumably you were also doing research and advocacy for personal assistance services in the U.S. Were you able, in your work with other organizations, to impart some of this knowledge you were learning about how the European system worked? Did it have any effect on the legislation that you were trying to develop?

Heumann: WID held a series of meetings over the course of the ten years that I was there that dealt with personal assistance services. When we did national meetings, we always brought people from other countries in, so that people met people from other countries. We would have panels, and in the materials that we produced, we included information on international issues. When we got the international grant that provided money for people to go abroad, one of our priority areas was personal assistance services. There were one or more disabled people that went over to study the models, to talk to people, to learn the pros and cons, and then monographs would be published and distributed. I don't want to say that most people today think about the international models when they're looking at PAS, but certainly there was an exposure. People read the documents, and participated in the meetings, to learn from people about problem areas and areas of concern.

[Tape 31, Side B]

Empowerment, a key lesson

Heumann: I think that empowerment is one thing that people in other countries learn from us. I don't know if they learned it from us, but it helped reinforce things that they were trying to do. People were amazed at things like the 504 demonstrations, and suing for employment discrimination. Litigation is something that isn't done very much in other countries, you would talk to people in Japan where a lawsuit could take ten or twenty years to go through the system. Their systems of government was so different in so many ways. I think it helped some people, there was a cross-fertilization.

Landes: Do you think that work had any impact legislatively in the United States?

Heumann: I think it helped some of us. We certainly talked about it, when we were working on the issue of people being able to be more self-directing. At the same time that we were evaluating what was going on in this country, there were many pockets of programs—. If you looked across the board at the people in the U.S. who needed personal assistance services and people in Europe that needed personal assistance services, you found that there were programs that served pockets of people. Even the most progressive programs there, were still limited. The government, like here, was concerned about programs getting too big.

I think there are these common themes. If you were strong and advocated heavily, you could get some smaller demonstration projects set up. There was still this reluctance to allow these programs to get too big, because government was always concerned, here or there, with the dollar amount. Everybody was, and is, trying to persuade government that personal assistance services, putting more money into certain types of programs, in the long run economically makes sense. It enables people to have the resources that they need to go to school and get a job. I think all of us were, and are still dealing with getting policy makers and others to really understand what it is we're talking about. The risks are only taken very incrementally.

Landes: You're talking about on the part of the policy makers.

Heumann: And legislators, who are policy makers. I think in all arenas, disabled people were and are still not yet having the level of influence that we believe we need to have. Disabled Peoples' International was started in '80 or '81, and Ed was involved in that. Ed was on the first board. DPI has really helped to both create disability rights organizations throughout the world, and help to create this network. The U.S. is not a big player in the international arena, in anything. We view ourselves as, by and large—what can we learn from those other people—we know it all.

Landes: Are you talking about the United States overall, or just the disabled movement?

Heumann: The disabled movement. I think that statement is true overall, but in the disability community it's been very difficult to get a lot of involvement from people in programs like DPI.

Landes: I take it that was a trend that you were pushing to get. To get more people and more organizations of people with disabilities involved with international groups.

Heumann: We felt that we could learn from each other. We felt that the movement itself was internationally small. The goals of the countries were all very similar, so we should really be a partner in what was going on. I think that WID was and is one of the few organizations that focuses on international activities. Leadership development, women's issues, I think they've played an important role in networking disabled people from around the world together. In a small way, but I think what they've done has been very important.

WID successes internationally

Landes: Is there a particular success that you or WID had in the international arena that you could point to?

Heumann: Yes, I think what I've been talking about. The work that we did in other countries, the work that we did when people came over to the U.S. Helping to share ideas, inform public policy here and abroad, and being a network. You have processes like Ralf Hodgkiss' and Susan Sygall's the Wheelchair Project and Mobility International. WID, Ralf, and Susan were three of the groups that were disabled run and doing work in other countries. Bruce Curtis was doing work at CIL and at WID, and with Ralph. We helped be supportive. I think from a public policy perspective, what we did that hadn't been done was to be able to get disabled people to go abroad to learn, and to write. To be able to share information on public policy related issues.

As far as the legislation is concerned, the legislation on personal assistance services, there is still no real national legislation on personal assistance services. There's the MiCASSA [Medicaid Community Attendant Services and Supports Act] bill that is being continuously worked on, which would do Medicaid reform and allow people who are Medicaid eligible to receive services. There are changes that went on with Ticket to Work, which allows states to create buy-in programs for disabled people to be able to work and buy into Medicaid. There are more programs out there than when WID started in '82 and '83. Still there is yet to be national legislation which takes what we learned. They think that a lot of the work that Simi Litvak and the others did at WID was very important and informative. It allowed us to get a much clearer picture of what was going on in the country. That program really gave a voice to what people with different disabilities and ages said they needed in the personal assistance services arena. All of that is good.

At the end of the day, there still wasn't enough money. Money was frequently a problem. There wasn't enough money to take what we were learning and have the kind of influence needed to make things happen. ADAPT has been doing some very good work in continuing to move the personal assistance services agenda forward. That was one of the things with WID, to be able to do the necessary public policy work, work with legislators and give them what they needed in order to be able to look at doing legislation. At the same time you had to keep very much involved with the community and the grassroots and getting them involved.

Work on multicultural women's issues

Landes: You've also mentioned that you were involved with women's issues at WID. What would be some examples of work that you did on women's issues?

Heumann: Certainly a lot of the aging work was primarily focused on women. I also participated in some national conferences on women's issues before WID and after WID. In 1980 I had been named by *Ms*. [*Magazine*] as one of the eighty women to watch in the eighties. I participated in local and national conferences. Things were all mixing together. I was certainly involved with women who were doing the primary work on women's issues. The Marsha Saxton's of the world, and Adrienne Ashe's of the world. When I went to government, it's where I really had more of an ability to help move forward both the international agenda and the women's agenda. I could put money into programs to get things started, that I didn't have at WID or CIL.

Landes: How did you see your role? Were you bringing the issue of disability to these other organizations that were primarily concerned with other nondisability related issues in women?

Heumann: In the seventies and eighties, when I was involved in women-related activities, I was involved locally in a group called the Women's Economic Agenda Project. That was a nondisability group that decided early on to integrate disability into its work. I got on its board, and that was another way that I was invited to participate in some other conferences. As you were saying, one of the big issues was to get people to acknowledge that disabled girls and women did experience discrimination—

Landes: —as women.

Heumann: As women, it was a combination. The women's community frequently did not acknowledge disabled girls and women as a part of the movement. They had the same fears and concerns about disabled girls and women as other people did. I think we've been trucking ahead with that. Being on the Women's Economic Agenda Board was helpful.

Landes: What did you learn from that experience?

Heumann: I learned more about some of the multicultural issues that were going on, locally and nationally. It helped introduce me to women from the minority communities and learn more about their issues, and them learn more about our issues. It basically exposed me to new things, and allowed me to develop friendships with people. In developing friendships with people, it allowed us to learn more from each other and look at some of the common barriers. I think that the women of color community felt very much like the disabled women's community that the women's movement was controlled by white, nondisabled people. There was difficulty in getting other issues, and other constituencies, integrated into the women's agenda. That was a good thing to be able to be working on together.

How was I involved in women's issues? It was kind of a part of my life. At one point, the National Council on Independent Living didn't have a lot of women in positions of authority. There had never been a woman chairperson of the board. I, with a group of other women, got Marca Bristo to run and got her elected as the chair. I experienced, throughout my career, this feeling that disabled men are in a hierarchy above disabled women. The experience that I had with the WID board kind of typified many of the issues that we would talk about by ourselves. Women were working in the independent living centers and even as executive directors. One of the reasons for that was that there was less money in the program. They would take jobs that paid less. Men wouldn't work in those jobs, in many cases, because the pay was too low.

One of the things that has been going on for me over the years, has been the ability to be with other disabled women and talk with other disabled women about sexism and how it plays in our lives. Trying to focus attention on issues for disabled girls and women, so that they can have more positive experiences. You've got all these different discriminations that are going on. When you add race, poverty, disability, or sexual preference, the more overlays you have, the more the problems exist. Around the women's community issue I would say that I have been part of what has gone on with the women's movement. It's an important part of what I do. I think I try to be a role model for other girls and women. That is what many of the disabled women are trying to do, to be role models for others. To show that we did it, you can do it. Breaking stereotypes about roles in education, roles in work.

Beijing Conference on Women and the International Disabled Women's Conference

Heumann: I think in government, what I was able to do on the women's agenda, when I was the assistant secretary of the Department of Education, I was one of the forty-two women who went to the Beijing Conference on Women. There were forty-two delegates that the U.S. officially sent, and I was one of those delegates. It allowed me within the U.S. delegation, to raise disabled women's issues and girls' issues, and to be able to participate in a pre-conference and a conference afterwards to work with disabled women from other countries who were official delegates about getting language into the platform of action. Being able to be supportive of the disabled women who participated in the Beijing conference who were part of the NGO meeting. As a result of that, I also served on the Clinton inter-agency council on women. That allowed me to continue on the national level to continue raising issues affecting disabled girls and women.

One of the results of the Beijing conference was that our office took a leadership role in getting other federal agencies and foundations to sponsor the first U.S. sponsored international disabled women's conference. In 1997, we had an international women's conference which brought more than 600 women from around the world together. It was a very collaborative effort, some government agencies, mainly the private sector. There were women from every continent. There were great materials that were produced as a result of that conference. Videos and books sharing the findings of what had happened at the conference. There were a series of other meetings focused on disabled women in the United States, on employment issues that were supported by our office, the Department of Education and other federal agencies. One on Native American employment issues. I think those meetings helped other disabled women, like Cathy Martinez, get involved in other national women's organizations. Through many of these involvements we've seen other disabled women getting involved in national women's organizations and helping to continue to integrate our issues into the bigger agenda. We, the Department of Education, also supported other international activities. We gave $200,000 to Disabled Peoples' International for their world congress in Mexico. That had never happened before.

Landes: I take it you had a strong hand in that?

Heumann: Yes, I was the boss. There was certainly opposition to some of that internally. We shouldn't do that, we shouldn't be putting our money there, but we did. It was helpful for what it was able to do. In looking at international issues, we're still incrementally moving forward in trying to get the main governmental institutions and foundations to look at disability issues and to really integrate disability into the work that they're doing. We just made some small improvements.

Landes: Is there anything else you'd like to say about your work in the women's movements and the intersection between women and disability issues?

Heumann: I think that one of the ongoing problems is that if you look at who disabled people are, most people have invisible disabilities. If you look at disabled girls' issues, for example. There was a study that was done by the Department of Ed, a longitudinal study on disabled students which followed them for six to eight years. One of the findings of that study was that disabled eighteen-year-old girls were twice as likely to become pregnant single mothers as nondisabled girls. Trying to get people to understand who are disabled girls and women and the multiple problems that they're facing. How can the women's community, how can the government really look at the depth of the problem that many of these girls and women are facing? It's still one of the struggles. That is my ongoing commitment, to continue to work in these areas.

— 451 —

Management, program planning, and funding of research at WID

Landes: Another piece of your role at WID was management and program planning. What were your duties in those areas?

Heumann: As a founder and a member of the executive committee, I was very involved in figuring out what our priorities were, what grants we were going to go after, working on doing fund-raising, overseeing planning and implementation of projects.

Landes: Who was involved in the executive committee?

Heumann: It was Ed and Joan and myself. Over time, it changed with major heads of projects. As the organization got bigger, we brought on an administrator, a person in charge of accounting.

Landes: Who were those people?

Heumann: Cesar [Perrotti], I can't remember his last name, Marion [Conning], Debbie Kaplan, and Simi Litvak.

Landes: All of these people, at one time or another, joined you and Joan as part of the executive committee?

Heumann: Yes.

Landes: And what was the role of the executive committee?

Heumann: To oversee the operations of the organization. We would talk about what was happening, problems, things that we needed to do, opportunities.

Landes: Can you give an example of an issue that you would have to struggle with?

Heumann: Before Debbie came on, one of the questions was that Debbie wanted to come in and bring technology in as a new and emerging issue for the organization.

Landes: Specifically, what about technology?

Heumann: At that point, in the eighties, we knew that technology was starting to play a bigger role in the lives of people in the country, but that disabled people were not really benefiting. Debbie's proposal was to help elevate the discussion of technology and disability and to be able to get the big players in the field of technology to understand more of the issues around disability and technology, and to bring disabled people more into being involved with key people in the field of technology. Basically, to take another emerging issue and try to make sure that disability wasn't being excluded, but rather that the light could be shined on this issue and help correct the problem before it got out of control.

Landes: Was convincing those three to five to six of you a hard sell?

Heumann: We had to look at if there was money in this. If we picked up another new issue, were we going to be able to fund it? The bottom line was that as you picked up projects, you picked up staff. In the beginning, the organization agreed that it was an important issue and that Debbie would be a good person to come in and work on the issue. The organization was willing to float some money upfront as she was looking to get some grant money to carry it forward. I don't know that there were heavy duty discussions, but there were appropriate levels of discussion. In going after certain projects, whether it was a research and training center on independent living or personal assistance services, they were issues that needed to be discussed. How do we do it? How should it look? How do we know that we're doing our program development efficiently? Who is going to oversee it? How are we going to make sure that the whole thing comes together in a timely way?

We talked about issues around communication, and issues about how WID was selling itself publicly. It's basically the core group that deals with internal and external issues. It was a very important group in helping to guide the direction of the organization. I was on the board until I left, and being involved with the board and strategic planning was very important. With all of the groups that I've been involved with, whether it was Disabled In Action, or CIL, or WID, the organizations are still here. They are still viable.

[Tape 32, Side A]

Heumann: The organizations are still working in a direction of being a part of an overall disability rights movement, and still working to improve the quality of life for disabled people. A civil rights approach, and self-empowerment.

Landes: You were talking earlier about one of the issues you grappled with. For example, when Debbie wanted to bring in technology, you had to look at the money available. To what extent were the research areas dictated by availability of funds and funding?

Heumann: We never were able to get our research projects off the ground until we got funding. In the very beginning, when we started doing fund-raising to set WID up, it was to do things like research on personal assistance services. We used dollars that we had gotten from the private sector to begin to make the case for going after government money. In the personal assistance services arena, we used private money to begin to do research and then leveraged our ability to be able to go after federal funds to get a research and training center on personal assistance services. In the aging arena, I don't know that we ever got federal money or even state money. A lot of the work that we did on aging was funded by private foundations and corporations. Ultimately, we put forward what our agenda was, we did or didn't get the money.

Landes: Are there examples of areas where you really wanted to do research and advocacy that got left by the wayside because you weren't able to get funding?

Heumann: Internationally, we were never able to develop the international program to the extent that it needs to be developed. The bulk of money in international is from the federal government. There are some foundations that do international work, but we never were able to get more than little bits of money. The core dollars for international WID came from the NIDRR grant, which they've had since '88 or '90. They have re-competed for it a couple times. It's like four or five hundred thousand dollars. It's been the bulk of the money they've gotten. They got money from the federal agencies when they organized this women's conference. There were a couple hundred thousand dollars.

Landes: Which you had to fight for?

Heumann: In the end, I had to argue with people. I can only speak until '93 when I left, but I would say that was the most underfunded program. It's not to say that the other programs were funded at the level they needed to be funded. They weren't. But at least you got the feeling that there were more prospects out there, to be able to get more money to those programs.

WID's greatest impact: personal assistance services and technology

Landes: In what area do you feel that WID had the most success and its greatest impact?

Heumann: We were very helpful on the personal assistance services agenda, I think we really helped to do cross-disability coalition development on that issue. In the aging area, the work that was done helped educate many in leadership positions in the aging community. It helped some disabled people learn more about what was going on in the aging community. It was a relatively small program overall, but for the money that they had, it did some good work. The international work that's been done has been good. People recognize that the work that was done is very important. It's all small. Ralph's work, Suzy's work, our work, when you speak to the people who are working, they will say things are really good. When you look at the whole world arena, none of us have a very big effect. At least the way I would like to. In technology, there's been some really good work that's been done, and now they've gotten more money from another federal grant to help them continue the work.

Landes: Did you do any work in that, or was it primarily overseen as part of the executive committee?

Heumann: A lot of the technology work has been done since I left. The couple years prior to my leaving it was Debbie's project. I was very supportive of it because I thought it was a well thought-out approach. It followed very much the model that we used for other things. Meeting with people, working with people, helping them to understand disability issues.

Landes: For example, who did Debbie connect with?

Heumann: She connected with many of the designers in the field.

Landes: Are you talking about computers, what comes under the heading of technology?

Heumann: I don't know what they're all dealing with now.

Landes: When you were there?

Heumann: We were looking at hardware, software design. The importance of getting an understanding of what the barriers were that disabled people were facing in using hardware and software, coming up with discussions about how to involve disabled people to make sure that these issues were being identified and corrected early on. In the beginning, it was very much allowing people to understand who are disabled people, what are the issues, and why it was important, and why they should care and how to look within their own organizations and take these issues with consideration. At the same time it was working slowly with the government on these issues. Now that they've got this 508 money, I think that's really good. Debbie was also doing some work with a guy named Sam Simon. Sam was a guy in D.C. who was very big in the field of technology, don't ask me what. He was one of the big players.

Landes: What is 508?

Heumann: Section 508 is a provision of the rehab act which was first passed in 1988, and was revised in 1998 or 1999. It basically said that the federal government has an obligation to ensure that technology hardware and software is accessible to disabled people. Websites, computers, etcetera. It is a very important piece of legislation, because the government is a reasonably large purchaser of technology. So the hope is that getting 508 effectively implemented within government will necessitate that many of the designers of technology who wish to do business with the government have to understand and implement the standards into the work that they're doing or the government won't be a purchaser.

Landes: Were you at all involved in that?

Heumann: Yes, because 508 is part of the rehab act which was under my area of responsibility. I was involved on a committee within government to help strengthen the language. The Architectural Barriers Board was involved in developing the standards, and I was on the board. So I was involved that way along with a member of my staff.

Technology focus at the Department of Education

Landes: Is there anything more you want to say about the whole issue of technology? For example, to what extent were you directly involved at WID? Was there a specific aspect of Debbie's project that you were directly involved with or was it primarily oversight?

Heumann: It was really being a part of the senior leadership team and talking about what it was that she was thinking of doing, and being supportive of it. At that point, she was very knowledgeable about this issue, and very capable of moving forward on it. It was as much for me to be learning from her about what was going on. Today, I would say that technology is something that I also focused a lot of attention on within the Department of Education and the other agencies. Not so much as someone who was knowledgeable about what accessible technology is, but from a policy perspective.

I did a lot of work within the agency to get the agency to be ahead of the game on getting standards developed within the department on what accessibility was going to be, on

pushing the department to make sure that we did not bring in inaccessible technology. People in the department were knowledgeable about how to assist disabled people in getting the technology they needed, to get the ongoing training that they needed in order to use the technology. We got disabled people integrated into a technology team that I served on, a committee in the department that dealt with oversight for accessible technology.

Landes: What was the name of that committee?

Heumann: I don't remember. Technology also was something that Kate Seelman, who was the director of NIDRR, reported to me that they were doing a lot of work in technology. Kate played a very strong role within the department and within the government. There were a number of new initiatives that were directed towards NIDRR. We did an event in the White House where technology was brought into a White House meeting that was being held. That way the

President and Vice-President and the other participants could actually learn about the different technologies that were being funded by the government.

At the ADA celebration last year, there was a technology tent that was set up at the Vice-President's house to allow people to learn more about the breadth of new technology that was out there. A loan program was brought into the department which gave money to the states to get disabled people money they could borrow to purchase technology. The most important thing we were doing was being a partner in what other people in the private and public sector were doing to elevate discussions of technology. We focused a lot on technology and children. There was a report issued that talked for disabled people about the digital divide that came out of our office, which we used a lot in trying to help drive through the issue of what happens when disabled people don't benefit from technology. I think technology is one of the most critical areas right now, and we need to make sure that people have access to technology at age-appropriate times in their lives. This is another big problem, particularly for people who have more significant disabilities and people who are poor, who can't necessarily purchase the technology that they need.

There's a lot to say about technology. One of the things I tried to do in the department, for example there was the Office of Vocational and Adult Education which was given money to develop community technology centers. One of my concerns was that these community technology centers were not going to be either physically accessible or technologically accessible.

Landes: Describe what a community center was.

Heumann: The tech. centers were really supposed to be programs in the community that would allow local people to come in and learn about and use technology through the Office of Vocational and Adult Education. We were able to get them to include in our RFP they were putting out for a National Technological Assistance Center, that there would have to be a component in there on TA in the area of disability and accessibility. Mary Lester's project received $200,000 through that grant award to be able to provide technical assistance to these community projects. Not that much money, but it certainly was a success because we were able to integrate disability into a project that wasn't seen as a disability program. There are many things that are going on like that. You see the same patterns over and over again. Can you get disability integrated into the discussions from the beginning?

Landes: Always broadening the base, and broadening the number of issues that disability is becoming a part of.

Heumann: Right, because at the end of the day, disabled people need to be a part of everything that's going on. Unfortunately, that doesn't happen yet because there aren't enough disabled people yet who are at the design phase of many of these projects, whether it's technology or as these systems were developing. Elderly and people with disabilities, years and years ago, were not at the table working on it. We became victims of systems, and then we tried to fight against the systems that were set up. Fighting against racism, sexism, handicappism. One of the critical issues that we're still dealing with is education. More and more, if disabled people are not getting the education that they need, they're not going to be able to get the jobs they need to economically support themselves. More broadly they won't become the people who will be at the table, both in the design and implementation of whatever.

Landes: Because those skills are a gateway to jobs?

Heumann: Yes, chemistry and physics and algebra. Think about the fact that a truck driver twenty years ago could not necessarily be a truck driver today because trucks now use computers in their operations. If you have disabled boys or girls that are not learning about technology or using it in their education, you can only catch up on so many things. It gets back to one of the issues we were discussing earlier about CIL. You still have the majority of disabled people being people who became disabled later in life. There has not yet been enough emphasis although it is increasing, for disabled adults to really focus on the importance of education, both for kids and for higher education.

Lack of oversight of institutions of higher education and recruitment

Heumann: There is not enough emphasis placed on the whole issue of lifelong learning. You see that when you look at the fact that there's not that much that the disability community is really doing to put pressure on the community colleges and universities. Outside of getting disabled student programs in place, there's not that much that's really been done in terms of looking at recruitment of disabled people into their programs. We're doing disability studies programs, which I think is very—.

Nothing that's going on is bad. Disability Studies programs are very important, the disabled students programs are very important, certainly quality programs. Still we have not yet focused enough on what is happening when universities go to recruit students. Are they really looking at disabled people who are Asian and black and Latino and white and Native American when they're looking at recruitment? Do they understand about learning disabilities and all these other issues? What I learned through my work at the department was that you have two million jobs in the area of education that are going to be opening up over the next five to eight years. You have very few disabled people who are entering—

Landes: So you're talking about teachers, teachers aides—

Heumann: —teachers. Just teachers, I'm not talking about aides. There is going to be a need for two million new teachers because of the number of people retiring and the number of kids coming into the system. You could look at that as a great opportunity for people to get jobs, yet there are still relatively few disabled people moving into careers as teachers.

Landes: It sounds like you would question whether the Department of Education and the various schools and universities are really doing an adequate job of recruiting people with disabilities.

Heumann: Yes, in any arena. You don't really see it a lot. You hear discussions going on about the problems of the anti-affirmative action movement and its effect on minorities. You don't hear a lot about what's going on in higher education with disabled people. We did some stuff at the department, we thought that the parent training programs, and DREF, and Protection and Advocacy, and the groups that are doing litigation for kids who are having problems—. But who is monitoring from within the disability community what the higher ed. community is doing? It's because we have limited resources and people are still trying to handle the basics.

Landes: Is anybody that you know of attempting to deal with that issue?

Heumann: There are programs out there. There's the HEATH [formerly Higher Education and the Handicapped; now the HEATH Resource Center] Project, and another organization that basically represents the disabled students' programs from the university perspective, not from the disability perspective [AHEAD (Association on Higher Education and Disability)]. The HEATH Project has been trying to provide information about what colleges and communities are doing. This other organization is sharing information on what the disabled students' programs are doing.

Landes: Is the HEATH project a government organization?

Heumann: No, it is a government funded NGO. There were those projects. The data is showing that more disabled people are going to colleges than before. But there isn't any group or groups that are really focusing on holding colleges and universities accountable. There is no right to higher education for anybody. 504 and ADA are really individual complaint oriented. It's one of the other areas that we're still needing to work on.

Appointment as Assistant Secretary in the Department of Education

Landes: We've merged into talking more about education and your work at the Department of Education. I'd like to back up a little bit and talk about how you got appointed. What was that process like? Were you contacted or were people in the disabilities organizations advocating that you or someone like you be employed?

Heumann: I worked on the campaign, on the Clinton campaign. Then I got a call in December from a guy named Bobby Simpson, who had been the head of the Disabled People for Clinton in '92. He asked me if I was interested in working for the administration, and if so, on what type of job? I said the only job I was interested in was the Assistant Secretary position, and if it didn't work out, no hard feelings.

I didn't want to do anything else. I hadn't really thought a lot about it, but what I had learned from working in State Rehab and other jobs was that I didn't want to work at a job where I wasn't reasonably responsible for what was going to happen. I didn't want to be the director of rehab. I didn't want any of these positions. I was also concerned about leaving WID because I liked being here and I liked the work I was doing. I wondered what it would be like if I went back to D.C., how was I going to survive back there as a disabled person? That was in December. Then I got a call in February asking me to come in for an interview for the Assistant Secretary position with the Secretary.

Landes: Who at that time was—?

Heumann: [Secretary of Education Richard W.] Riley, he was appointed and confirmed in January. I went in to do an interview. Within a week or two weeks I got a call from him saying that they wanted to offer me the job.

Landes: What was the interview like?

Heumann: It was very interesting. It was interesting for me because I basically decided that I was going to be myself, and if I didn't get the job, it was okay. What was important for me to do in that interview was find out who they were and let them know who I was, to see whether or not we could work together. I was a little bit nervous, but not that nervous because my life didn't depend on it. They asked me questions about myself, about my background, the work that I had done, what I thought the issues were, my management experience. Anyway, the interview was very interesting. Riley has a disability.

Landes: What was his disability?

Heumann: In the navy, he contracted some virus, and his spinal column is fused. He leans over when he walks, he can't turn his head. On the one hand, he would never call himself a disabled person. But he doesn't flinch at being called a disabled person. Over the course of the years, one of the things that we got him to do at certain presentations, was to talk about his experiences becoming disabled. That was important for other people to hear. The interview itself was a good interview.

Landes: What did they tell you about who they were, that you didn't expect?

Heumann: I have to think about this one particular part of the interview, but the bottom line was that Riley himself was not uncomfortable around disabled people or me. I did not feel that he was uncomfortable around me. He was very genuine and we got along very well. Madelaine Kunin, on the other hand, was more uncomfortable around disability issues.

Landes: The issues, or the people themselves?

Heumann: Both.

[Tape 32, Side B]

Relationship with Secretary Riley

Landes: We're talking about the interview with Secretary Riley.

Heumann: I left the interview feeling comfortable, like I had been myself, that I had in a relatively sort period of time—. I had never met Riley before, I had never met Kunin before, and so it was important for me to tell them my views on things, to see how they reacted. At the end of the day Riley reacted fine, my feeling at the end of my eight years working with him was that if he hired you, he believed in you. He would listen carefully to recommendations that you made, he wouldn't always agree with what you wanted to do. But at the end of the day, over those eight years, he focused a lot of attention on our issues, more than any other secretary had done before. He really felt comfortable in what he was doing.

Landes: You thought you had good access to him?

Heumann: Yes, I always did.

Controversial issue of discipline of disabled children in public schools

Landes: Were there times that you wanted to do something that he turned down?

Heumann: Yes, some of the controversial issues that we worked on, particularly around discipline. That was a big issue.

Landes: What was the issue?

Heumann: One of the big issues that I worked on over the seven-and-a-half or eight [years] had to do with disabled children who had emotional or behavioral problems. Problems that resulted in them not acting appropriately in school. The educational community had a big push to try to get disabled children, whose inappropriate behavior in school was not the result of their disability—they were arguably bad kids and you couldn't say it was the disability that caused them to be bad kids—to get them treated the same as nondisabled kids. In today's lingo, in many states around the U.S., kids who do certain things can be expelled from school for up to year.

Landes: Zero tolerance.

Heumann: Zero tolerance, precisely. We worked really hard on saying that disabled kids should not have educational services cut off from them, even if what they were doing was not the result of their disability per se. A policy of no cessation of services was really a lot of what we were working on.

Landes: So you, as Assistant Secretary of Education, was really pushing that particular policy?

Heumann: Right, the parents were supportive of it, the disability rights organizations were supportive of it, but the unions—. The unions theoretically supported no cessation, but they wanted the ability to remove kids earlier. The school boards wanted to be able to get them out of school. We spent a lot of time working on this issue and trying to develop compromises that, at the end of the day, wouldn't adversely affect disabled kids too much. There was no way that they weren't going to be adversely affected by the changes that the educational community was pushing.

I would honestly say that, by and large, he very much believes that no child's education should be cut off. He supported the positions that we were developing, which worked very hard on making sure that even if a kid was put out of school because of a gun or drugs or violent behavior, that they still had to receive some form of educational services. That was against the advice of many of his advisors.

Landes: So he ended up supporting it?

Heumann: Yes, in the very beginning some of the people around him said no way. They wanted us to drop it, it was too hot an issue. He was great, and he chaired a meeting with eighteen organizations on a Saturday morning to learn more about the problem, and to get the different perspectives on the issues. He put a work group together that was chaired by myself and his deputy, to meet with the groups to look at solutions to the problem. He met with parents, he met with educational groups, he did a lot on our issues. I felt that he was very accessible. I think people felt that he was very accessible to many groups.

Major focus areas as assistant secretary

Landes: In what way did your previous work in the independent living movement and advocacy work from New York through Berkeley and at WID prepare you for this job?

Heumann: I knew a lot of people. The jobs had all afforded me an opportunity to meet people from around the country in the disability community, and to some degree in the parent community. I knew many of the national people who worked in the national groups that did advocacy on disabilities. They weren't necessarily disabled people themselves, in many cases they weren't.

I had a reasonable understanding of Washington from the job that I had working in the Senate and the committees that I had been on over the years, and the testifying I had done and the work I had done around ADA and 504.

I understood the rehab system, I understood special education to some degree, I understood NIDDR to some degree, and I understood from myself and my friends what it was we were ultimately trying to do. I was reasonably prepared for the job. There's no way you can be completely prepared for that job.

Landes: What were your major areas of responsibility?

Heumann: I was in an office of 370 people and a budget of $10.5 billion.

Landes: What types of programs?

Heumann: All special education, all rehabilitation, and all programs under the National Institution on Disability and Rehabilitation Research. There was a director of special ed, of NIDDR, and a commissioner for rehab. So I oversaw the development of the special ed legislation, the rehab legislation, the NIDRR legislation. I oversaw the development of regulation, the development of grants, awarding of grants, working on the senior leadership team for the department, working on getting disability integrated into the overall agenda of the department.

Landes: Beyond your specific areas of expertise.

Heumann: Not expertise, but of responsibility. What we were trying to do in the department was getting the offices to work more closely together. The higher ed office, the secondary ed. office, the voc ed office. Part of what I was doing was getting my staff integrated onto work teams in the department as the department was in the beginning looking at restructuring. To try to get disability discussed anyplace and everyplace, to try to get linkages together so that issues affecting disabled people were not just dealt with in our office, but were integrated more broadly into the agenda of the department. We were somewhat successful on that.

We were involved with the President's Task Force on Employment of People with Disabilities. The secretary was on that committee, and I was his designated representative. Our office did a lot of work with the task force on issues around transition for disabled kids, a whole bunch of stuff. We played an important role in the work that that task force was doing. We were on the Architectural Barriers Board, which dealt with a myriad of issues including section 508. The standards in the area of architectural design.

One of the areas that I really focused on was also what was happening to minorities with disabilities, from preschool on up. I put on a number of staff people who were minorities themselves, who had knowledge about disabilities, some had disabilities themselves. We began to do work in the area of homelessness and migrant ed issues.

Landes: So by homelessness, you mean seeing that homeless people are afforded the opportunity—

Heumann: It was policy at this point. We were linking up with other government programs that looked at issues around homelessness, and trying to get them to focus on disability. Then getting our staff to understand about the issue of homelessness and disabled individuals. Also to get people knowledgeable about migrant ed. issues, or for disabled people who were migrant workers, or migrants with disabled children. We started a number of projects.

One was a National Technical Assistance Center on Native American issues. Another two that are going to be started in the next couple of months, one a National Technical Assistance Center on Latin Americans with Disabilities, and another National Technical Assistance Center for Asian Americans with Disabilities.

Peer review panels restructured

Heumann: When I first came in, the peer review committees, those that read the grants that organizations apply for, there are panels of three to five people that do grants. We have hundreds of grants that we give out, and hundreds and hundreds of applications that come in for some of the competitions. Some of the competitions may be twenty or thirty applications, some may be a couple hundred applications.

So the peer review panels, we got it as a requirement that there had to be at least one disabled person and one person of color. It was basically what I was trying to do, and how I was prepared for my other jobs was that I was knowledgeable about issues that affected disabled people across the board, and reasonably knowledgeable about problems that were going on among racial minority communities. When I went in to that job, I was very committed to make sure that we would do our work differently and highlight issues that hadn't been highlighted before, and put money into some of those program areas, trying to get the hiring of disabled people and views from the disabled community integrated more into the general grants that were given.

So they didn't focus as much just on the professional's perspective on what should be happening, but also acknowledge the parent's perspective and the disabled person's perspective. We got more money into independent living over the last eight years, more money into parent training programs. We developed community parent projects which were focused on helping develop organizations in the inner cities and underserved communities around the U.S.

Landes: It sounds like one of the areas that you're really trying to serve was that previously underserved communities were getting more attention on the issues of disability.

Heumann: And we were putting money into helping that happen. You could define it as leadership development.

Biggest challenge: being a person with a disability in the department

Landes: Earlier I had asked you to what extent your previous work in the movement had prepared you for the job. You said, bottom line, nothing quite prepares you for this job. So what were some of the surprises? What were your biggest challenges when you came on?

Heumann: In the beginning, one of my biggest challenges was being a disabled person in this job.

Landes: Why?

Heumann: My peers outside of my office, in many cases, had never worked with a disabled person as a peer. This part was amazing.

Landes: Are there some anecdotes?

Heumann: Yes, I can tell you anything. Certain things can't be publicly discussed for twenty years. One day a person called me who was another assistant secretary. There was me, and this other person who called me, she was calling me to tell me that one of the assistant secretaries was leaving, and that she wanted to have a party at her house for this person. She wanted to let me know that her house was not accessible. I said, "That's not a problem, we could do it at my house." She said, no, she wasn't calling to ask to use my house, she was calling to let me know that she was going to be doing this and she knew that I wasn't going to be able to come, because her house wasn't accessible.

Landes: That was very decent of her.

Heumann: [laughter] I remember when I realized what was being said, I was completely blown away.

Landes: What was your response to her?

Heumann: My response, "When are you having it?" She was having it when I was on travel. So I said, "Oh well, I'm on travel." In the very beginning, there were a number of incidents. There was one woman who was in a senior position who knew nothing about disability and continually wanted to engage me in discussions that were below a 101A level of disability. I was a provider of information, and it was awkward, because it felt very voyeuristic. I'm a very open person to talk about disability; it's nothing that I feel uncomfortable about.

The department had, on a monthly basis, a satellite conference that was linked all over the country. Secretary hosted, it was an hour discussion on different topics. They would bring experts in to present information. We were using the Chamber of Commerce, because the Chamber gave the space for free. I didn't go to the first one, and I went to the second one. When I got to the second one, there was a big flight of stairs in the front. I found out that I had to go through the kitchen, and I was furious. At our next senior staff meeting, I raised the issue. I said that I thought we needed to change where we hold these meetings, because it's not accessible; I had to go through the kitchen. It was the decision of the senior leadership team that they would not change the venue.

A couple of weeks later, there was an article in the newspaper, a picture with a caption underneath it. There had been a group of disabled people that had picketed in front of the Chamber of Commerce, protesting its lack of accessibility. What I found out was that the Chamber was supposed to make itself accessible earlier, and had reneged on its commitment to do that. I didn't know any of the people involved in the demonstration. I didn't know the demonstration had happened until I read the article in the *Washington Post*. I get a call into the deputy secretary's office. The discussion starts out, "I don't believe in coincidences." I had no idea what this was about. He showed me this picture, and I said, "Okay. Clearly he thinks that I organized this demonstration." I knew nothing about it and to this day have no idea who was involved. I said, "I saw that article, too. I have no idea what this is all about, except that I had heard that the Chamber had reneged on a commitment to make itself accessible." I guess these people were upset about it. We talked about it, and at the end of the meeting I said, "I hope you believe in coincidences now." I firmly believe that when I left that meeting he did not believe me. The senior leadership was a very diverse group, women, African Americans, Latinos...

Landes: This would be other assistant secretaries?

Heumann: Yes.

Landes: How many were there?

Heumann: Eight or nine, and then there were the deputies to the secretary, there were a couple of those. There was one guy who had a learning disability, but outside of that, nobody. I think in the very beginning, for the first two to three years, it didn't alter the way I did my work as far as creating ideas and moving my agenda forward, but in the first couple years a lot of the things that I talked about were somewhat suspect.

Landes: Because you were new to people?

Heumann: Yes, because no one had talked to people about things like when the department is dealing with things like technology, we have to make sure technology is accessible. People said, "How are we going to do this? How much money is it going to be?" On a more fundamental level, the person who called me about the party, she was the general counsel for the agency and a minority woman. The other woman who was dealing with me on disability issues, I don't even want to remember everything that went on with it, she was also a minority woman.

Landes: You felt that they were condescending to you?

Heumann: If I had called the person who called me and said, I'm going to have a party, but because of my neighborhood, you can't come in my front door, or you can't come at all—. Nobody though anything about it. What really struck me was that I was dealing with people who were peers and had major responsibility in the agency to oversee public policy for all constituents, who were not dealing with disability equally.

I have to say, over the course of the years, a lot of that changed. People learned a lot more, thought a lot more, and a lot of those experiences didn't occur after the first couple of years. Outside of the fact that the work itself was voluminous, and the job that I had was the kind of job where—. There was an assistant secretary, a director of special ed., a director of NIDDR, and a commissioner of rehab. You could have let each one of those people run their own offices and done very little with them. But my approach was to get the offices to work more collaboratively together, selecting themes that all of the programs should have been looking at. I did a lot of work on management, because of staff morale issues. I worked every day, twelve to fourteen hours a day. I felt that overall, a lot of good things happened. The pace is very fast. There's an amazing amount of things that you have to learn. You have to learn, learn, learn, learn, learn; you have to gain confidence, get people you can trust, people who will get information when you need it, and make sure to get a really good staff of people.

Hiring staff with disabilities and racial minorities

Landes: Did you hire a lot of disabled people on your staff?

Heumann: There were two levels of staff, the other political staff, there were nine of us all together.

Landes: By political you mean political appointees?

Heumann: Right, the commissioner of rehab was disabled, my deputy was disabled, the director of NIDRR was disabled. The director of Special Ed was not disabled. My special assistants, a couple of them had disabilities and were a racially diverse group of staff. For the civil service people, we did a lot over the eight years. When I first came in, there was a downsizing going on.

Landes: Across the entire department?

Heumann: Right. When I came in, there were about 402 people on my staff and the number was going to go down to 320, but we were able to keep the number at 376 when I left. We actually picked up some new positions, and I think we did a reasonably good job on bringing in both disabled people and racial minorities, some of whom had disabilities across the board in the organization, and some who didn't. I think that was good. From the secretary on down, there was an open-door policy for people to talk about what they liked and what they didn't like. Overall, the agency was better for the work that went on.

Major successes as Assistant Secretary of Education

Landes: What do you consider your major success while you were there?

Heumann: One of the major successes was on cultural diversity. We were able to bring in a more culturally diverse group of staff and were able to bring cultural difference and disability more into the peer review process. We were able to help enable through the scoring process for grants that we set up to enroll more disabled people and people of color—for grantees to recognize that they needed to emphasize bringing diversity into their staff, and we were able to give a number of pretty significant grants exclusively focusing on populations of disabled people from different racial backgrounds.

I think we brought attention to issues on things like homelessness and migrant ed, we did more work internationally with Mexico and Ireland in bilateral agreements between the U.S. and Ireland. I guess we got disability more integrated into the work that was going on in the department overall.

Landes: Not only in the areas where you had responsibility, but in the entire Department of Education.

Heumann: We tried to influence all of the offices within the Department to be doing more in disability. We touched every office to look at disability more than they did before. In areas like technology and accessibility, we did have a good effect. One of the contributions that the disabled political employees made across government was that we were able to elevate the discussions around the needs of disabled people and the role and responsibilities of government to look at those issues differently.

Landes: Are there one or two areas where you feel your goals weren't achieved? Where you feel that there were major gaps that you weren't able to close?

Heumann: I think in education overall, there's still the ongoing problem of kids not receiving the services that they should be receiving. We strengthened the monitoring system that was going on a lot in special ed. But, in saying that, it's having an effect, but the bottom line is that there are still too many kids who are not getting what they should be getting. The system is not responding appropriately. We've made more progress in getting kids better services. We've elevated a number of things, including kids in state and local assessment processes that were going on, which will bring another whole view to what's happening to disabled kids and their learning. There's still not enough agreement and acceptance that disabled kids can learn, they have a right to learn, and its the system's responsibility across the board.

Susan T. Brown

Interviewer Regional Oral History Office Disability Rights and Independent Living Movement Oral History Series

At the time of her interview with Judith Heumann, Susan Brown was employed by the US Department of Education as a personal assistant to Ms. Heumann, who was then assistant secretary of the Office of Special Education and Rehabilitative Services. Ms. Brown had been involved for many years in the disability movement, as an information manager for the World Institute on Disability. She played a key role in organizing "Celebrating Diversity," a symposium for and about disabled women in 1995. She also assisted in organizing the International Leadership Forum for Women with Disabilities, a five-day conference held in Bethesda, Maryland in 1997.

Susan Brown graduated from Bryn Mawr College, majoring in Russian. She holds an American Sign Language certificate. In 1999, she was accepted as a Peace Corps volunteer and resigned from the oral history project.

David Landes

Interviewer/Editor Regional Oral History Office Disability Rights and Independent Living Movement Oral History Series

David Landes received a B.A. in Economics from Antioch College and an M.A. and Ph.D. from Washington University. He has taught economics in Bay Area state universities and community colleges since 1970. He currently is an instructor of Economics at City College of San Francisco.

As a result of an auto accident, Dr. Landes has been a quadriplegic since 1962. He became active in the disability rights movement in San Jose, California, in 1977. He subsequently worked in the Counseling Department at Berkeley's Center for Independent Living and at the Computer Technologies Program. He was active in the Disabled International Support Effort (DISE) 1980-89. With DISE he worked with disabled organizations in Nicaragua, El Salvador, and Cuba as part of the effort to provide technical and material support.

Dr. Landes became interested in oral history while working with his mother on her memoirs. He was an interviewer/editor with the Regional Oral History Office from 1996 to 2001.

Jonathan M. Young

Interviewer Regional Oral History Office Disability Rights and Independent Living Movement Oral History Series

At the time of his work with the Regional Oral History Office, Jonathan Young was a Ph.D. candidate in American history at the University of North Carolina at Chapel Hill, writing his doctoral disseration on the history of the Americans with Disabilities Act and the disability rights movement, and a project director at the National Rehabilitation Hospital Research Center. During the course of conducting the oral history with Judith Heumann, he was appointed associate director for Disability Outreach in the White House Office of Public Liaison, during the Clinton administration.

Dr. Young has since received his doctorate in history and is attending Yale School of Law. He is a recipient of the prestigious US Jaycee's "Ten Outstanding Americans Award."