



Disability Rights and Independent Living Movement Oral History Project

Issues of Life, Death, and Identity: The Role of Disability Advocacy and Scholarship

Diane Coleman: State and National Organizer for ADAPT, Founder of Not Dead Yet

Carol Gill: Scholar and Advocate on Issues of Disability Culture, Health, and Bioethics

**Interviews conducted by
Kathy Cowan
in 2002**

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

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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.

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Diane Coleman

State and National Organizer for ADAPT, Founder of Not Dead Yet

**Interviews conducted by
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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.

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All uses of this manuscript are covered by a legal agreement between The Regents of the University of California and Diane Coleman, dated August 9, 2002. 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.

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Interview History—Diane Coleman

Diane Coleman brings a unique perspective to the Disability Rights and Independent Living Movement Project because of her writings and activism on issues of disability and assisted suicide, and her leadership in ADAPT, a grassroots direct-action organization focusing particularly on personal care assistance and transportation access. She has been disabled since birth and has used a wheelchair since the age of eleven.

Ms. Coleman was a board member of the Westside Center for Independent Living in Los Angeles in the early 1980s, where she met disability activists Carol Gill, Paul Longmore, Barbara Waxman, June Kailes, Doug Martin, and others and was introduced to the idea of a disability culture and to issues which would occupy her attention for the next twenty years. In her interview, Ms. Coleman recounts her early life and education in Michigan, her college years at the University of Illinois, and her move to California to attend the University of California at Los Angeles, where she achieved a law degree and a master's degree in business administration.

Her oral history reflects her developing sense of identity as a person with a disability and her growing awareness of the need for a broadly conceived disability rights movement. She describes her efforts as an

organizer and activist, participating in protests questioning the concept of "right to die" for severely disabled people and demonstrations for accessible transportation as a leader of ADAPT. She recounts her move to Tennessee, where she founded an ADAPT chapter and became codirector of the Tennessee Technology Center. In 1996, Ms. Coleman helped to found, and suggested the name of, the organization Not Dead Yet, conceived of as a "street group" to bring public attention to issues of euthanasia and assisted suicide as they relate to people with disabilities.

Ms. Coleman is currently the executive director of the Progress Center for Independent Living in Forest Park, Illinois, a suburb of Chicago. She took several hours from her working day for this interview, which was held at the Progress Center in one long session, with a break for lunch, on August 9, 2002.

The transcribed interview was audited and lightly edited by the interviewer and returned to Ms. Coleman, who reviewed the transcript with careful attention, correcting errors of transcription, punctuation, and spelling of names, but making no substantive changes in the transcript.

Kathy Cowan
Interviewer/Editor
August 9, 2002

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Childhood, disability diagnosis, and special education in elementary school

[Interview: August 9, 2002] [Tape 1, Side A]

1

Cowan: This is Kathy Cowan interviewing Diane Coleman, August 9, 2002. We are at Progress Center for Independent Living in Forest Park, Illinois, near Chicago. Diane, let's begin with your early childhood. Would you like to say something about your parents?

Coleman: I'm adopted. I was adopted at ten days old, roughly. I later found out that my biological mother was from Latvia and came over when she was about eight years old, with her family in the early fifties. No, that's not right. She came over at age eight, and by 1953, when I was born, she was nineteen. Her family came over during World War II, in that phase when there were problems happening over there. My parents adopted me because they thought they could not have any other children. They had not had any children in the beginning of their marriage and it took a long waiting list to adopt at that time. I think they waited a number of years, and then when they were five years married, they adopted me. Then they promptly began to have children, four of them after that. So, I have four siblings.

My father was, at that time, working for Ingersoll-Rand as a drafting person, drafting schematics for boats, I believe. His father had worked for Gibson guitar, making guitars, and had a third grade education—his father did. My father had gone to college. My mother was a homemaker, and we lived in post-World War II housing. You know, little box houses that were developed in suburbs of towns in Michigan.

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

Cowan: What kind of kid were you?

Coleman: When I was about six months old, they discovered that I had a dislocated hip. So, we went through a series of operations and full body casting 'til that issue was corrected.

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By the age of two, I was out of the cast. My mother was, at that time, pregnant for her first natural born child. I was slow to learn to walk, but they thought it was because of that issue. By the time I was six, they figured I was having enough trouble climbing steps and things like that, that there must be something else going on. I remember those years as very happy years, with friends around.

The thing that was hard was not always being able to keep up. For example, in kindergarten, I didn't play in the playground. I was going to get knocked down if I did. If I tried to play the kinds of things the other kids were doing, I would fall down and get hurt. I felt left out in that regard, but otherwise I had friends at home, and we played in the sandbox, and I had a good time.

When I was six, they decided that I had muscular dystrophy, which was incorrect. They, I found out later, told my parents that I would die by the age of twelve, which was not true either, obviously. It took a few more years for them to decide, when I was nine, to send me to one of the clinics here in Chicago, to have a fuller diagnosis. They determined then that I had spinal muscular atrophy.

Cowan: What was the reaction of your parents on the first diagnosis. Do you recall?

Coleman: They didn't tell me.

Cowan: They didn't tell you?

Coleman: Oh, of course not. Oh, they told me I had muscular dystrophy, but they didn't tell me the grim theory and encouraged me to go to school, and concentrate on, you know, doing what I was doing. In my earlier years too, I should mention, they were very open about the adoption. They used to read us all—all the kids—a book called *The Adopted Family* to explain about adoption, and how they love me just as much. They set a very good stage for handling that.

Cowan: That's how they knew who the birth mother was.

Coleman: They don't.

Cowan: Oh, they don't.

Coleman: Oh, no, all they know is that little piece of information. You know, there's a little bit of information from the foundling home. Anyway, then, after I was correctly diagnosed, after mainstream kindergarten, the result of the diagnosis was to put me in segregated special ed.

Cowan: The first diagnosis?

Coleman: Yes, the first diagnosis. I was put in segregated special ed, for grades one through six.

Cowan: Was that a separate school? A special school?

Coleman: Yes.

Cowan: What was the name of that?

Coleman: It was called Upjohn School. It was named after Upjohn Company, which was based in Battlecreek, Michigan, fifteen minutes away from Kalamazoo. Upjohn School was attached by a corridor to a another school—a regular kids' school. I remember every Thursday—I think it was Thursday—we used to go to the library there. They would have "handicapped kids" go to the library, and it felt like they cleared the corridors, so that nobody would see us. We would go to the library, get our books, and come back to our segregated school. What was provided at that school was physical therapy and occupational therapy, as well as the curriculum. They had classrooms that had basically, a first and second grade, third and fourth grade, fifth and sixth grade—three separate classrooms.

Cowan: Lots of children in this school?

Coleman: There were—I was on the lower floor, and each classroom probably had, I'd estimate about twenty, twenty-five kids.

Cowan: Of every kind of disabilities?

Coleman: Physical disabilities, and some developmental. They had the kids who were deaf or blind upstairs; we didn't generally mix.

Cowan: And why was that? What did you think about that?

Coleman: I didn't understand it really. I didn't understand it. Other than the idea that they were doing some different set of teaching methods or accommodations. I don't really know. We were all brought to school in buses that were just for us, so it was a very segregated situation. Now, this was in the fifties and early sixties. When I was in sixth grade, they made a decision to move me and one other girl into a mainstream middle school.

Cowan: Were you using a chair at the time?

Coleman: I started using a chair at age eleven, so yes, during sixth grade.

Cowan: What kind of reaction did you get from the other kids and teachers?

Coleman: Well, I wasn't the only kid in a wheelchair. I think that they handled it very well, actually. I was sort of impressed with how they did it. It was harder and harder for me to safely walk. I had braces on my feet, by then, to keep my ankles from collapsing, but I was unstable, and I was not very comfortable with crutches—I think I did try that for a while. I really wasn't physically comfortable with crutches, and they gave me a wheelchair to push, manual wheelchair to just push, because it gave me some stability and I could move along—kind of like a walker in its effect. But guess what? Whenever I felt too tired, I would just go sit in it. I would be sneaking in my own mind. I was sneaking, sitting in it. That was a transition, in other words, that they enabled me to choose for myself, at the pace I wanted to do it. When I was using the manual wheelchair, most of the time, then, they got me a motorized chair. All this, by the way, was done—I mean, all of the equipment issues, and many of the clinic issues—were handled through the Muscular Dystrophy Association.

One reaction of my family, particularly my mother, was to get involved with the Jerry Lewis Labor Day telethon stuff. I did not think anything bad about that, at that age. What I knew was that they were paying for things that otherwise we could not afford, and that the school was not providing. This was pre-education law requirements also. The diagnostic work that was done similarly, would not have been done without them. Obviously, I think the health care system should provide all of this, then we wouldn't need any of that. Anyway, they became involved in it.

Cowan: Were you involved? Were you part of any of it?

Coleman: A little bit. Once in a while, they would have a local program—TV or whatever, and they might interview me and my mom, and I'd get to say one word, or something. I'd be the cute little kid. But I was never a "poster child"—I wasn't that cute. [Laughs] That's what it is, right? I didn't look that good. But, they found it somewhat interesting to have me on a number of times.

Family attitudes about disability and education

Cowan: So you're beginning to feel identified as a person with a disability?

Coleman: No, no, absolutely not. Other than in a bad way. Disability is bad—that's how I was raised. That part of you is bad. What's good about you is these other things, but what you need to do is accomplish in spite of your disability, which is a bad thing. Now, I'm not saying that was emphasized—it was just understood.

My family certainly supported me to concentrate on school. My father was a big factor in that. His belief was that I would need to concentrate on getting a good education, and excelling in school to the greatest extent I could, because otherwise, I would not be able to earn a living. They were not always going to be there, and I needed to be able to do that. He felt that I needed to develop something that would be enough to enable me to achieve financial self-sufficiency. He often thought that what that ought to be was writing. In fact, throughout my education, including all the way to graduation from graduate school, he believed that I would not be able to make it in what he termed, "the real world," in the public. But when I graduated with a MBA and a juris doctor from UCLA, he thought I should become a computer programmer for a law firm. I wasn't involved in computer programming, but he thought I could sell myself that way. He did not think I was going to sell myself as a lawyer, in spite of my education and the level I had gone through. He really had a very hard time believing I would be able to be accepted in the general workplace.

Cowan: And yet, he encouraged you—

Coleman: Yet he encouraged me to do all my education. He never put barriers. He might not like it—like for example, in high school, I did chemistry. I was into science—I was going to be a scientist, was my original plan. I took quite a bit of chemistry and other things, but chemistry was the one that scared him, because what if I spilled a chemical, an acid, on myself, in that process, but he didn't stop me from doing it. That would be basically, the

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way my parents operated. They might not have agreed with every choice I made, but they let me make these choices. They encouraged me to pursue my education very, very seriously.

To some extent, they enabled me to do other things, socially, but it was hard. Transportation was difficult—anywhere I wanted to go, I'd have my parents with me. I didn't get to do after

school things, the same way other kids did. So, I used my time in the late afternoon and evening to study; it was useful. The hard thing was—I had two sisters and two brothers. There's good and bad to what they—in particular, what my father did on those issues.

The other thing he did, which was devastating to me, was that he conveyed to me, that one of the reasons I had to be financially sufficient was because, "Let's face it, you're never going to get married." He said this to me, when I was about thirteen. My sisters did not get that message. They were not pushed to work hard in school.

Cowan: Because they were going to get married.

Coleman: They were going to get married, and some other situation was going to take care of their needs, but I needed to be self-sufficient.

Cowan: The positive message for you—

Coleman: Well, it enabled me to go into the workplace in the future, and that carried—I didn't carry self-doubt or a grudge about being a woman with a career. I didn't care that somebody told me I wasn't going to have a career because of my that, because of my gender. It was convenient, because I was in a field of men, and I felt like I could hold my own just fine. I know a number of women around me had a feeling that they had to overcome that. I noted I did not have that. So, something about what he did was good.

Cowan: Not an unusual message, in those days, for women, that you're going to get married.

Coleman: Right. That part was very damaging.

Cowan: And hurtful. What kind of reaction did your brothers and sisters—were they resentful of the time your parents spent? Did they feel you were a person with a disability and that was a problem for the family? Did they have any kind of—

Coleman: I think my sister probably resented the fact that I didn't have as much housework assigned to me as she did. I had a little, but she had more assigned to her, and that wasn't really fair. It was very stressful on my mother—probably one of the hardest things. By the time I was in my early teens, by the time I was in a wheelchair, I needed help to get up and down from a seated position, even though I could still bear weight. That meant, every transfer, she had to assist me with. I was put in a Milwaukee brace, throughout my teenage years, prior to being able to have a spinal fusion. The management of that Milwaukee brace—

Cowan: Which is?

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Coleman: Which is a brace that goes from hips to chin, and holds your back from becoming severely curved—more severely curved than it was. But the management of that brace and the foot braces was a process that took time and energy. At night, I had to wear the braces on my feet, but I could only tolerate them until one or two a.m. Then I would have to call her and have her take them off—every night, unless we decided to have a night where I wouldn't have them, which didn't happen often. They really followed the protocol that they were told to follow. So there's mom going through all these stresses of having to be there all the time, or make sure she was available when I needed to go to the bathroom. She couldn't go away a lot. Besides that, she had four more kids. At a certain point, it was too many kids. My siblings probably, if they were considered today, they would have been labeled as ADD [Attention Deficit Disorder]. In

fact, their kids have a tendency to have ADD. They were a little wild; they were pretty wild kids. In a way, I was easy, in the sense that I was a little goody-two-shoes kid. Merry Sunshine, as one teacher used to call me—I hated that, but it was nevertheless the case that I learned how to conduct myself in a way that would be successful with those around me. Many disabled kids learn that. I learned that, and my siblings were wild, so I was easier in that sense, even though I was physically more work. It was just a lot to put on my mom, who I'm sure was quite relieved, as she became an empty nest. She's enjoying this part.

Cowan: What was going on in school? There were no physical barriers? You could use a chair in school, no stairs?

Coleman: As to the Upjohn School, that was all true. But in middle school and high school, the schools themselves were accessible. They were relatively new. You could get in and get around. All the corridors—they were ramped. The bathrooms were—I don't know if they had enlarged stalls or not. What I remember about that time, is that they made an arrangement with a slightly older girl that lived in our neighborhood and attended the school. She assisted me, one time a day, to transfer onto the commode and use the restroom and go back to class. It's kind of funny because I don't remember that that happened every year. I'm not sure when it stopped. At some time, it did stop, and I had to undertake the process of not drinking until a certain time of day, which I did in my work life as well, until things changed.

Cowan: Were you thinking of yourself or were other kids viewing you as a person with a disability? Were you identifying yourself that way?

Coleman: I was a wheelchair user, and I was one of two in a school of few hundred. I felt very much the odd one out. It took a while to get friends. It took 'til my third year in middle school to have what I would say was a group of friends, and that was very hard. I did feel that I was the odd one, and not part of the acceptable group. It got a little better in high school. I tended to hang out then, with the geek group, I would say—the science-math group. Some of us also were able to hang out with the group of people that was engaged in creative writing. That was the late-sixties development of the counterculture. I began to get a little bit connected with that. I studied too hard to be acceptable to the counterculture group in high school. But then, in college, that changed. You could be a good student and still be accepted in the counterculture in college, so that made it easier.

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Choosing a college, surgery, and developing assistive devices for independent living

Cowan: What was the transition from high school to college? How did you decide to go—did people discourage—I mean, I know your father was supportive, but your counselors—?

Coleman: The counselors were encouraging that I should go to college. They prepared me with academic coursework that was on the college track without a doubt. In fact, I was able to place out of the first level of my science and math. I had a spinal fusion between high school and college, which took me out of commission, in that regard, for about a year and a half.

Cowan: Oh, that's a long time.

Coleman: I was in a rehab hospital for a year, laying down on a Stryker bed, which would flip you like a—you know, it would put you in a sandwich and flip you over. I was able to use that time to take some classes by correspondence from the University of Wisconsin, that were beneficial when I was able to start college in residence. Before I had the spinal fusion, my family had—we had explored colleges. The feelings that the counselors seemed to have was that there was not sufficient access at the colleges in Michigan to meet my needs. Certainly, the ones in Kalamazoo were absolutely completely inaccessible. The couple of schools in Michigan that were possible didn't have really an adequate set up, and there was no such thing as personal assistance.

Cowan: That wasn't a concept yet—

Coleman: Not yet really there. Barely there. Certainly not there in Michigan at the time, from what I can tell. Nobody in my circles had ever heard of it anyway. So, what they wanted to do was to get me to the most accessible school, which was University of Illinois at Champaign-Urbana. So, we went down there. I applied, and they make you come down there and be interviewed by the people at the rehab center there. This would've been in 1969 or 1970.

I went down there, and I had a private meeting with an occupational therapist there to discuss activities of daily living, because at that time they had what they called the quad house for men who were quads, who were living in the house that had PAs [Personal Assistants] on staff at the house. They didn't have any such thing for women. So, if I was going to the University of Illinois, I had to be physically independent and not need a PA. So, here I am, with the Milwaukee brace, knowing that in a couple of years I'll be without the brace, but not knowing what to do with that, because every rehab that I had ever had, with all the assistive devices and all, they were not very useful. I knew nothing about how to transfer. They had no ideas, and they were not very competent, now that I realize. But this occupational therapist at that University of Illinois was actually very sharp. He had a wall full of devices, as if you were looking at a catalog, nowadays. He discussed with me, for a half an hour, the daily tasks that one would do from the moment of waking up, to the moment of being in bed. Basically, in that conversation, helped me go through a problem solving process, and talked about the importance of doing each thing step-by-step, figuring out the obstacle, and thinking about a possible tool.

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Cowan: That is very good.

Coleman: We had no idea if it would work. So, I get out of the hospital two years later, go home. My brother and I went through a process that I had been starting to think about and designed equipment for me, which he made in the garage.

Cowan: That's fascinating. Can you give me an example of something?

Coleman: Sure. One of them is—while this got remade later—a reacher. This reacher has a hook on the top for picking things up, and it has something on the bottom, a fork, if you will, that I can use to push things away. What I use it for mainly is dressing. It's pretty effective. And everybody is individually different. Obviously the key thing was the transfer board.

Cowan: This tape is going run out, so let's do that on the next side.

[Tape 1, Side B]

Cowan: Diane, would you like to explain the transfer board, you designed one.

Coleman: Yeah, we had to design one. A transfer board, as you know, is a bridge between one type of chair and another. The problem with that kind of a bridge, the standard off-the-shelf model when you are moving on it, if you don't have strong arms and hands to push it and keep it where it belongs, while you scoot across it, it's going to land you on the floor, so I needed one that would be stable while I moved on it. What we basically designed was a board that, on the far end, toward which I would be transferring, had a flap that would stick down inside the toilet seat commode, or the shower bench, and you know, a little cut-away in the shower bench, so that when I was moving onto these things, it would not go forward. Behind that flap, about a toilet seat width distance from it, is another little barricade underneath the sliding board, so that the transfer board cannot move in either direction when you're getting on the other seat, or off. The front part is on a hinge so it also works getting in and out of bed. We worked out the various techniques. I had no choice because they didn't have PAs. I worked out these techniques because I was very definitely wanting to get away. I wanted to have a life, I wanted to go on to college, and I wanted to have an independent life. I did not want to stay home with my family.

Cowan: You needed these gadgets?

Coleman: I needed them. We had to figure it out. We insisted. I insisted. My brother, who was sixteen at the time, was like, "Yup, I'm going to do it." He thought about—now, the transfer board is thirty years old. It's still here, and in good shape, and he made it out of—He explored types of wood, and then put twenty coats of shellac on it. He selected white beech, one of the hardest woods there is, got it all designed, and we worked it out on the details. It still functions; it hasn't fallen apart yet. It's probably going to last the rest of my life.

Cowan: He should've patented his design.

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Coleman: Oh, we thought about that a bunch of times, and just haven't done it. I actually presented about the transfer board to an occupational therapy conference. The thing about my elementary school occupational therapy was they had us weaving baskets and making potholders and doing nothing practical whatsoever about activities of daily living, which is really sad. I know they've gotten away from that now, fortunately, but it was very sad that that's the way they were doing things then, because I could have done more, had I known anything about these kinds of devices.

Cowan: So between high school and college, you had visited the campus, seen this occupational therapist who talked about daily living, then you went to have your spinal fusion, and then you applied again—or then you really went to—

Coleman: Then I completed getting myself physically ready to do it. I actually went down there. My parents drove me down there to college, and at that point I had not yet worked out how am I going to shower. But they thought I could, at the most accessible dormitory, which was Florida Avenue Residence. It was the one that had the roll-in showers with no lip. No lip on the floor, no barrier. They took an OT [Occupational Therapist] then, from the rehab center, and we went over to the Florida Avenue Residence showers and worked out a method, and I was able to complete my bachelor's there.

University of Illinois, 1974-1976, rejecting a disability identity

Cowan: Now, there was a bigger community of people with disabilities on that campus, wasn't there?

Coleman: Yes.

Cowan: Did you make contact with them?

Coleman: Yes, I still felt, as I had been raised to feel, that I'm not "handicapped." I'm not like "that." Whatever that image is, that negative thing, I'm not that. I didn't ever want to be associated with a group that was about disability. That would only label me and limit me—that's how I saw it, and I didn't want that. I wanted to be an outsider to that. Nevertheless, throughout my life, if I look at who my closest friends were, in middle school, high school, and college, most of them had disabilities or otherwise didn't quite "fit in." We didn't talk about disabilities much, but we accepted each other.

I mean, it amazes me now when I look back, but one of my closest friends in college was Gayle Hafner, who also ended up becoming a lawyer, and is now an organizer with ADAPT [American Disabled for Accessible Transit; now American Disabled for Attendant Programs] in Maryland. We spent plenty of time together, and we didn't do a whole lot of talking about disability. We weren't into disability identity, per se. We felt unfairly treated, so what we did was compare notes about being treated badly, in some situations, or having difficulties in our social lives. I guess that's the seed of disability awareness—sharing those stories. But we had not worked it through at all. I know I had the idea in my mind that I could compare my experiences, and I did, through high school, to other minority group experiences, emotionally, but I didn't believe it. I didn't

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believe that we, as a group, were a minority. I just felt there was something unfair about some things that were happening to me, and I related very much to the black civil rights movement—the struggle and the inequity and injustice. I saw it as to me, but not me as part of a group. It just wasn't there. Nope, it didn't, not that easily. I was still worried about escaping. I wanted to escape the identity I was being assigned, and I thought the only way to do that was to reject that part of my identity and prove that I could do what my dad was telling me to do. Prove yourself.

Cowan: What kinds of barriers and problems did you encounter at the University of Illinois that you felt was unfair?

Coleman: The laboratory was inaccessible, and I ended up changing my career plan, from being a scientist to going into being a psychologist, which was okay at that point because it was again, the early seventies, the counterculture movement. It fit fine, for me to make that change but the lab was inaccessible. There were no PA services. My real issues were issues pertaining to social relationships. The social rejection—that was what really got to me. And, some concerns about employment in the future. I was worried about that.

Cowan: By social relationships, do you mean with other individuals, with other groups?

Coleman: Mainly men.

Cowan: Mainly men?

Coleman: Mainly men. Men were an issue, absolutely. Now, at that point, I did have a boyfriend, who I'd been seeing off and on since high school.

Cowan: He came to the University of Illinois?

Coleman: Yes, he became a student there, eventually, as well. He was a nondisabled guy. Of course, I had to go with a non-disabled guy because that's what you gotta do, if you're going to be not part of the, not be labeled, not be limited. You're going to be just as good as anybody else, blah blah blah. That was where I was at. We were very close—he really accepted me. We were close because he was kind of an odd person himself, in his own way, and had difficulties with, you know, friendships, perhaps, in his early years too. So, we ended up getting married, and that's how I ended up in Los Angeles, because he was accepted at UCLA and their MBA program.

The disability program at Illinois

Cowan: Well, before we move on that far, were you aware of disability activities on campus?

Coleman: Oh sure.

Cowan: Were you part of them? What were you thinking about?

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Coleman: Well, I worked as a receptionist for a while, at the rehab center. There was the sports group. That was the main thing going on—there was a sports group. And I wasn't interested in sports at all, so that was the Champaign campus.

Cowan: So you finished up your degree there in psychology?

Coleman: Yes.

Cowan: And then decided to go to California.

Coleman: Got married, and went off.

Cowan: Were you aware of—besides the campus—anything going on in the disability movement in the country?

Coleman: Nope.

Cowan: No?

Coleman: Not at all. I did not see any publications. This is early seventies. I didn't know what was going on. Well, now I know, there was an independent living movement getting started, but I didn't know about it then. There was not a word that was shared with me. For all I know, the people at University of Illinois may have felt competitive, because that program was being led by non-disabled professionals.

Cowan: You mean, their independent living program?

Coleman: Yeah, their whole—everything. Right, there were non-disabled professionals at the University of Illinois, and I don't think they were out there encouraging people with disabilities to get into the self-leadership mode. In fact, I've talked to other people who were there, around that time, who felt they were extremely paternalistic, and invasive in their personal lives, as in, who are

you dating, and other such questions.

Cowan: You didn't get that?

Coleman: I didn't get that directly myself, but I wasn't very important to them, because I didn't get involved in the sports and the other activities. I was kind of, not relevant.

Cowan: Now, Timothy J. Nugent.

Coleman: Yeah, that's who I'm talking about. Him and his group. Now, I don't want to say anything bad about Tim Nugent. After all, he pioneered, and actually I received an award named after him, in my more recent years. But there was a feeling of paternalism in the process there. They were pioneering for their time, but either I wasn't—for all I know, they were telling people about stuff, but I didn't care. I wasn't reading disability publications. Nothing was coming at me, other than just daily life.

Cowan: And the activities of daily life—that was essential, wasn't it? You couldn't enroll in the University unless you could accomplish those on your own.

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Coleman: Yes, absolutely.

Cowan: For everybody?

Coleman: That was true for anyone attending there, except those who, for whatever reason, could afford their own personal assistant, and knew about it as a concept and could do it. Or, those four guys that lived in that house.

Cowan: They had something going.

Coleman: They had something going, yeah.

Move to California, thoughts on the influence of Tom Olin and the counterculture

Cowan: Well then, you graduated from the University of Illinois, with your husband, go to California, and what are you thinking about yourself, now? Going to start a new career? Going to go on in psychology? What was your plan?

Coleman: To try to get a job, at that point. I needed to support us for a little bit, while my husband went to school.

Cowan: And tell me again where you moved to.

Coleman: Los Angeles, Westwood, near the campus. I then went about looking for a job, and found a social worker, a master of social work person at a rehab center, in Northridge Hospital, a regular hospital, who wanted to experiment with having an actual person with a disability doing casework, and decided to waive the masters in social work requirement for hiring. I sent resumes all over the place, at that point. She picked up on it, and responded.

Cowan: Did you have a lot of turndowns? Did you experience a lot of barriers in getting that job, or did that just come pretty easily?

Coleman: I think there were not that many jobs for people with bachelor's in psychology. I worked for a couple of days doing telemarketing, things that I could not stand. I believe, even maybe in that phase, I may have worked briefly in an employment agency, but that was not the kind of work that was really suitable for me.

Cowan: What were the major influences in your college career, before you came to California. Were there any people that had a big impact on you at that time? Or events?

Coleman: I actually believe—When I was in the hospital for my spinal fusion, that's when I first met Tom Olin—Tom Olin, who is now the disability movement photographer. He went off after completing his community service as an orderly at that rehab hospital, because he was a conscientious objector who didn't qualify as a conscientious objector under federal law.

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Cowan: For the Vietnam War?

Coleman: Yes. After he was done with that, and I think a little bit of college, he went off to Arkansas to live, in a farm commune. The first summer that I was at the University of Illinois, after completing a semester, I went down there for six weeks, to, you know, be in this environment.

Cowan: You had stayed in touch with him since you met him?

Coleman: Off and on, very limited, but still, yeah. We had stayed in enough connection, and he actually stopped by the University of Illinois on his way there, to Arkansas. So, I knew about it, and we stayed in touch by writing because they didn't have phones at this place. They didn't have indoor bathrooms either. But I decided I was going to venture to go there. I had to go in my manual wheelchair, which I was generally in my manual wheelchair in my apartment. I moved out of Florida Avenue Residence into an apartment with two female roommates, during my time in college. I had gotten to the point where I could work out some additional flexibility about my physical environment. I decided that I would go ahead and venture to take a six week trip down there and experience this farm commune, and it was a very important experience to me.

When I returned, what I thought I would do was complete my degree in psychology, but we were living on a dollar a day down there, so I figured, "You know, I'll find myself a rich client, who'd like to get away from it all also and could afford to pay me thirty dollars a month and spend thirty dollars a month on themselves, and we'll just go down there, that'll be a great way to live." And that's what I thought I was going to do—I thought I was going to do for a while. [Laughing] Then that didn't pan out, and I changed my thoughts on that. That was really because of the relationship with the man I married, which revised my direction.

Cowan: Well, was Tom Olin working, except in a rehab hospital, in a disabled community in any way?

Coleman: No, he went away from that for a long time after that.

Cowan: So, he was influential, but not in that direction.

Coleman: Not yet. Well, what was interesting was not related to disability. We came back to that later.

Cowan: But he had a big impact on you, your early—

Coleman: Yes. You know, the other thing about that experience was he gave me a lot of books to read, especially when I was in the hospital. A lot of philosophy books. I got a minor in philosophy. Those philosophy books—a lot of ideas on different philosophies and different

religions—caused me to develop my own that influenced my sense of shaping the direction of my own life, and trying to be of service, and trying to be alert to opportunities, to use whatever skills I could develop, to be of service. Reading those books, and getting oriented that way in my early twenties, was very, very important. Being a part of the counterculture was very important. That was the time when, if it hadn't been clear to me before, it became really clear to me then: my goal in any career

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development was to be of service and to be able to function. I need to make enough money to function, and that's all. I don't need more. The point is to be useful, and that was what I thought. If I hadn't had those kind of influences then, maybe I would've found the same thing, but that was how I found it.

Cowan: Would you care to say, what you mean by counterculture?

Coleman: Sure—The peace movement, hippies, the people who were politically or socially rejecting the so-called establishment's status quo set of values. But what I thought was important about it, and would reflect, you know, I would say, later—all too many of my friends or colleagues at the time, they were more into the "sex, drugs, and rock and roll" part of it, than they were into the values of the peace movement and the civil rights movement. It was those values that were the most central element to many, and that's the part that I wanted to hold onto.

Cowan: Were you much of a political person? Were you engaged in any of the protests or demonstrations at that time?

Coleman: Not really. I think I felt too young and the opportunities did not present themselves in Champaign-Urbana, Illinois, I guess. And during some of it, I was in the hospital, and during high school, of course, I was completely cut off by not having transportation.

Cowan: But these values were really a part of your life, by the time you left the University of Illinois?

Entering JD/MBA program at UCLA, 1977-1981

Coleman: Yeah, I knew then that I wanted to try to do—and became more so.

By the time I left and I was just biding my time while my husband got through his education, but I think one year into his, I then began my own graduate education. That was 1977. I chose to enter the MBA and JD program at UCLA. There was a joint degree program. Normally, those degrees are three years for the JD and two years for the MBA, but they would combine them and have crossover classes for some issues. Basically, you could complete them in four years total, and that's what I decided to do. My reason for doing that was, I had missed the peace movement, as far as being able to be a protester/radical, but I really felt bad that the government hadn't said "yes" to all those people. Various phases of government—judges, the executive branch, the three branches of government, the legislature, had not done right. I thought, well, I want to get myself in a position where I could follow whatever course opens in front of me; I could follow that course and have the educational qualifications to pursue it. I want to be ready to be inside, to be inside the government, in the right spot, to say "yes" when those protesters come knocking on my door—that was my theory. And little did I know that it would end up by the time I graduated, that there weren't all that many protestors still out there, and I was needed more to do the protesting and organizing activity than I would be needed inside saying "yes."

Cowan: I see.

Coleman: But that was okay, because it still gave me a good education and it's been useful.

Cowan: Before you started that, what values did you get out of your experience at Northridge Hospital, where you were a medical caseworker?

Coleman: For like nine months.

Cowan: Was that an important period for you?

Coleman: I didn't learn a whole lot because I had a lot of experience with rehab and my own life coming into it, and I met plenty of people when I was in the rehab hospitals, both when I was twelve I was in there for a while, and when I was eighteen/nineteen, I was in there for a year. I was more able, I think, to help people have a more optimistic outlook about their situation more from seeing me be about in the environment. I think that was the theory that the supervisor in that unit had, is that the messenger is at least as important as the message. That was good, but I was really just waiting to get into the graduate education.

Cowan: At this point were you aware of any kind of disability movement action going on?

Coleman: Still not.

Cowan: Still not?

Coleman: Still not. I think where I first started encountering it was when I was at UCLA. Somewhere in there, I met Doug [Douglas A.] Martin. Doug was at UCLA quite a bit. He later became the 504 coordinator for them, but he was involved in a project called High School High-Tech. I think that project exists in different places. It had an element of peer mentoring—not mentoring exactly—it wasn't developed like that—but having adults with disabilities who had pursued education and career, talking to younger people that were more late high school. I remember going to a few events that Doug would invite me to.

Cowan: And how did you meet him?

Coleman: At UCLA somewhere. I think it was probably the Disabled Student Office, or something. I did use resources. UCLA had some serious accessibility problems. The bathrooms weren't accessible enough in any of the schools I was at there—the management school or the law school at the time, so that was really difficult. Somehow, in the course of time, he ended up inviting me—I guess we kept on knowing each other, but we didn't really get directly involved, and I didn't get involved in any disabled student services activities. I don't even know if they had any. They didn't have anything they were advertising a lot, because I went there enough that if there were big posters on the wall, I probably would've known. I think they were more traditional rehab oriented in a lot of ways. After that, after graduating, I still had some connections with Doug. Within, maybe a year or so, he invited me onto the board for the Westside Center for Independent Living, or generated them inviting me on. They had a nominating committee, and I got nominated.

Work experiences, thoughts on a charity vs. a rights model

[Tape 2, Side A]

Cowan: So, do you want to say a little more about that period when you were working at the Northridge Hospital in California?

Coleman: I got a lot of positive feedback from the supervisor about my skill level. That was my first successful job experience. I did a part-time receptionist thing at the University of Illinois. They didn't like me there—I was too busy reading homework while at the reception desk. They wanted me to get into their stuff, and I didn't. I'd read, and if someone came knocking on my window, I'd go, "Yes, can I help?" and I'd answer the phone. I did my duty, but I was just trying to make a little money.

Cowan: Was that at Northridge as well?

Coleman: No, that was at University of Illinois, and that was my first job. I would not say it was a successful job experience, because they didn't like me, by the end, and I didn't hold onto it too long. At Northridge Hospital, I felt successful. That's important in developing. I was successful in the "real world," even though my dad didn't think I necessarily would be. I had found an environment that was very workable. But I still wanted to go further, and he'd always encouraged me to get a graduate education too, because if you do that you have much better chances of sustaining, and earning enough to support yourself. In graduate school, I had two summer jobs, one with the Securities and Exchange Commission, and one with the Federal Trade Commission. My reason for those two was because I figured I was going to go work for the government. That's who's willing to hire disabled people and I can feel fairly confident that if I do a good job they'll probably want me, because they need competent people with disabilities to meet their quotas.

Cowan: You were thinking it through.

Coleman: Well, it seemed fairly obvious that that was the deal. So, I got these internships or summer jobs and did well in them. They were each, if you will, consumer-protection oriented. That is, they were dealing with law enforcement issues relating to what corporate America does to the system. Kind of like early Enron, you know. So, it was fun, and actually when I finished graduate school, I had been hired. I had a contract, an offer, and acceptance with Federal Trade Commission for permanent employment. That was when Ronald Reagan came into office and promptly cancelled all those employment arrangements. So I was basically, before I started the job, laid off and had a year of unemployment after graduate school—very difficult.

I looked and looked and looked, and I interviewed, and no private firm would hire me. A few of them were honest enough to say, "I don't think the client would be comfortable. I can see that your qualifications are very good, but I just don't think the clients would be comfortable." Most of them, I would never get a second interview. I didn't tell them in the resume that I had a disability background. I would send them a resume that looked like, "Oh, yeah, I'm going to interview that person." Then they'd

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see me in person, and it would be very polite, very polite, with a few that would admit what they really felt.

In fact, at some point along the way, I saw a survey of law firms, in California, indicating whether they would interview somebody with a disability. Would they hire a person with

a disability? About ten percent of them answered, "Uh uh," even though it was illegal in California at the time. This was pre-ADA, of course, so it was pretty amazing to me. But the agency in California that is the counterpart of the Securities and Exchange Commission was the Department of Corporations. That is a place that wanted to hire me and they were waiting for an opening to come up. The director there, in the enforcement division, was very eager and would call me, making sure I was still available, and waiting for that opening to come up, so he could hire me. I felt very positive in getting started there, and that experience—I was there for seven years—was very positive.

Cowan: Now, hadn't the Rehab Act of 1973 have been passed by then?

Coleman: That would be true.

Cowan: And 504, were you aware of that, or any of the 504 demonstrations?

Coleman: No, I wasn't. I had a basic idea that I probably had the right to have an accessible bathroom somehow, but I actually had to research that over time, because we didn't have it. Only when they remodeled the building, after I had already been working there for about four years and didn't start drinking until two in the afternoon. Only after I'd been there for a few years, did they do a remodeling and included putting in an accessible stall.

Cowan: And were you behind them doing that, or was that just because they remodeled—

Coleman: Well, I had said something. But, no, I didn't really agitate. Definitely not. I didn't really feel like that was the kind of thing that one should do. I think I was very much still, I think, feeling that charity model. I was raised on the charity model, right? Not the rights model. I mean, to this day, when my family members have, in three cases, had a lot of control over their own dwellings, two of them having been newly constructed, they have not made them accessible. They feel like they can just get me in by a carrier or ramp—we'll do something to get me in, but it's going to be awkward. It's going to be awkward. They feel like there's no reason to do something to create accessibility on that level when they can just put in a temporary ramp when I visit now and then. Even when my mother, who has diabetes and is in her seventies, just had a new house, kind of tract housing designed, maybe it's even really a condo—I'm not sure what it technically is—she could have asked for them to bevel the sidewalk up to the front door, instead of having the two-step, which is a small two-step. It would be easy, and I asked her to do that, before they were constructing it, and she wouldn't ask. She didn't feel that she could ask for that, and she's going to need it someday. She still didn't feel that it was okay to ask for that. That's how I got raised.

Cowan: And that's how she got raised.

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Coleman: Right, and that's how she got raised, and that's how I got raised. We're supposed to adjust ourselves, not society adjust itself. That's how I was raised.

Cowan: Not the rights model.

Coleman: Right, not the rights model. So, similarly, I didn't ask for that in my employment environment.

Learning to advocate at the California Department of Corporations, 1982-1989

Cowan: So what kinds of things were you doing everyday at the Department of Corporations.

Coleman: There were, statewide, twenty attorneys in the enforcement division. There were ten in the Los Angeles office. We basically worked to stop violations of various kinds of laws relating to fraud. Investment fraud was about seventy percent of our work. We also regulated HMOs [Health Management Organizations], and one of my first cases was shutting down an HMO called Medicaid. In California, Medicaid is MediCal, and they named themselves Medicaid, as part of their little creation of the image of reliability, and we dealt with mortgage companies and other financial companies.

My work consisted of probably at least half administrative proceedings that I would work with auditors—examiners, as they were called, who would go and look at the books and records and compile the accounting information, and investigators, who would interview witnesses who lost their life savings or whatever. They would then bring this evidence—they would package it up—and bring the evidence, and it would be reviewed by an attorney, me or others, to determine if there were violations and if there were, what would be the appropriate remedy, given the array available to us. So my job was evaluating that evidence, somewhat responding to customer letters too, and occasionally a legislative letter about violations and people basically losing their money.

We dealt with—you look at movie, "The Boiler Room," for example. Southern California and Florida are the two greatest states for people who do boiler room fraud to be, because two o'clock in the afternoon if you're at California, you can stop being on the phone and go down to the beach, and snort your cocaine. You don't need to be calling the East Coast anymore, by two o'clock. So, we were dealing with that kind of thing, and some things that were a little less dramatic—real estate scams, and all kinds of things, and shutting down companies.

So, either stopping violations—you can get injunctions, settlement agreements, or stopping violations by actually taking over a company, and it would either be an administrative process, which would involve taking away a license of a company that was licensed by us. That would involve—I did a few trials, what you would call administrative trials, where you'd have your opening statements and your witnesses and your documentary evidence and then your closing arguments to see what the judge decides.

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There's a lot of writing in the job, a lot of writing. I learned a lot more about writing than I already knew, and I, all my life, had been moving along in that category. There were civil proceedings. You could be in a mound of paperwork, but you'd have to take them to court. To take away that "nice businessman's" business, and occasionally, a businesswoman—not as often—is quite a mound of paperwork. You could have four inches thick of paper with evidence, and then you have to talk about the evidence. "You'll see from exhibit this, that they did that," and it can get very—assembling that evidence and presenting it to a judge who's going to see it for about an hour, and have to decide if he's going to let you put a receiver into that company and stop the bad guy from doing their thing and freeze their bank accounts, and try to get as much money back for the investors as possible—those are pretty big decisions. You have to get it all laid out. It could take six months to put together a really big case. I got to do all that.

Probably what was most useful about it, besides building confidence, was learning how to work with facts and evidence to persuade in an advocacy situation, and how to approach the dialogue about it with a certain level, type of authority in the tone that I would use—because I had the authority to shut a licensee company down, in effect. We would usually—most non-licensee companies got away with it, though, because there weren't enough resources in ten attorneys. So you pick the big cases. You could call them in. If you thought they weren't going to run away with the money, you could call the party into your office then, and there they'd bring their attorneys. You could have a room full of six business people and their attorneys, and little old me, sitting there, saying, "Here's what we're going to do, and you have to decide if you're going to stipulate to the following remedies, or I'll see you in court tomorrow."

Cowan: That must have been very empowering.

Coleman: Oh, it's very empowering. We, as a team, the examiners, the investigators, the lawyers involved—I mean, each lawyer pretty much handled their own cases—but it was empowering to experience that. It was useful to see how to do that. I didn't have to be mean—I could be nice while I did it. All of that fed into my current style, I feel, and sense of how to organize evidence, because if you had a complicated case, you had to distill it, and organize it and present it so a judge could absorb it quickly.

Cowan: Something you really couldn't learn in law school.

Coleman: Oh, no.

Cowan: On the job.

Coleman: It was on the job doing it, yes. Really, that's what you have to do in advocacy, I think too—in a lot of cases.

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The Westside Center for Independent Living, 1980s, the Bouvia "right-to-die" case, meeting Carol Gill

Cowan: Really was useful for that. Well, were you thinking, well, this is comfy, I'm going to stay here for the rest of my life? Or were you starting to think—

Coleman: Well, I worked there from '82 to '89 and in '82, that's the year I was invited onto the WCIL board.

Cowan: Oh, '82?

Coleman: Mhmm. At that point, I began to feel part of the movement. In effect, when I had been invited onto that board, by then, as I had started this Department of Corporations job, and I was quickly able to assume my responsibilities, and get good feedback, I felt kind of freed from the "you've got to prove you can work in the real world" thing. I did feel like I had kind of done that. I was then on my way in a career. I was making a living, and by then I was divorced. So I was making a living by myself. I had friends, I had a life that was acceptable to me, had many positive aspects, some negative, but I felt like I had really crossed a milestone in some ways.

Being invited, then, into the movement, and being with Doug, you know, starting with Doug, with him, and the others—June [Kailes], who I often had dinner with at Good Earth restaurant,

near the office there. She was very good about having a regular dinner with each board member—something I could learn from. And Carol Gill, and Paul Longmore and several others there, and in the surrounding community—Harlan Hahn, a lot of people.

Cowan: This was a real turning point for you.

Coleman: Oh, gee, think of who I was with. How were we all there, in one place, and at one time? I'm just this little baby—I don't know anything at all. I'm hanging out with these people at a reasonably increasing basis. They reminded me of myself. They obviously didn't buy into the characterization of who they were and the way their life was going to be limited the way society said, but they turned their reaction to that into a movement—not simply my personal battle against my personal oppression, but rather collective. That was just incredible. I can't even believe I was with people who were so effectively articulating the issues. Right about then, I'm starting to get *Disability Rag* —

Cowan: And that is?

Coleman: It is now *Ragged Edge*, but *Disability Rag* was the newspaper of the movement. I was reading it cover to cover, every time it came out. It would have articles by these people that I knew. Plus, there were other newsletters. There was the California Association of the Physically Handicapped, back then, and in spite of the bad name, they had quite a few activists in it, and I was reading their newsletter. I began to write for them, at times.

Cowan: Did you spontaneously submit, or did anyone approach you?

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Coleman: I think I submitted. I don't really remember when that started—exactly the writing part. I just remember, things gradually grew for me.

Cowan: Maybe you can say a few words about the Westside Center for Independent Living, and what it was. Was it just forming when you were invited onto the board, or was it already—

Coleman: When I first got to California, to L.A., and I was trying to get a job, I interviewed for the ED [executive director] job of that center when it was first forming out of somebody's basement or whatever. I was not remotely ready for such a job, I now know, I can tell you that. I now know, but I didn't know it then. I didn't know my limitations at all. Hey, I was fresh out of undergrad school. I definitely needed career development and mentoring, and they were quite smart not to hire me for that. But that was the year that they formed. That would be '79, no '76, maybe? Somewhere like that—'76, '77—before I got that Northridge Hospital job, and before I even started grad school. But then, I came back to them. Obviously they'd been in business for seven years or so.

Cowan: And what were they doing?

Coleman: Standard independent living center, I think. A large independent living center, without a doubt. I think their size was comparable to Access Living, relatively. I didn't have a full understanding of the programs. They were involved in advocacy, and that was the part that board members might become involved in. I also became, as a board member, involved in the technical aspects of board committee work, involving financial and organizational things that don't directly relate to the movement per se necessarily, but are just what is necessary to operate an entity, which I did need to know, very much, as it turned out. They had various programs, I think they did

personal assistance referral. I know they did housing referral, peer counseling—standard stuff.

Cowan: When you came on as a board member, this was a really turning point?

Coleman: It was important, it was. Just being able to talk to these individuals—I believe we must have had some connections outside of—I know we did—outside of WCIL, as well. The committee work—sometimes, the committees would meet at somebody's house. I don't really remember when each committee thing developed. I suspect I really didn't get involved more like till '85, at that level, very deeply. The last two years I was there, I was the board president. A major turning point occurred in 1985, from two—I think I was on little TV programs too, or little interview things. People would be developing videotapes for instructional purposes and, you know, they'd sit down and talk to Paul Longmore for a while, and they'd talk to Barbara Waxman for a while, talk to Carol Gill for a while, and then I'd get to talk too, not that I knew anything. I don't know, maybe they thought there was something interesting that I had to say, but I didn't feel like I knew anything. Then, in '85, two kind of big things happened. One is the Elizabeth Bouvia case. I got a phone call from WCIL, informing me that there was a protest over lunch hour, six blocks from my office, in front of the ACLU. And, you know what, and now I realize, that's how I met Carol Gill. That was '85. I didn't meet her at first. She wasn't on the regular board. She was connected to some of these people but we didn't actually encounter each other till then. That was our meeting.

Cowan: At the protest?

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Coleman: Yes, I went there. The protest was about this twenty-six-year-old woman with cerebral palsy who had had some serious setbacks in her life—miscarriage, marriage breakup, brother drowned, mother diagnosed with cancer—and she had been institutionalized as a kid. She checked herself into an area hospital and wanted to starve herself to death while receiving a morphine drip and comfort care. The hospital said no, and the ACLU found her a lawyer, the co-founder of the Hemlock Society, Richard Scott, to take her "right to die" case. They were processing that case through the system, and our basic reaction to it, as a community, was, "Wait a minute, you wouldn't be talking about it if she were non-disabled and had all those things happen. Why are you saying you should help her commit suicide?"

That court case lasted a while, but the protest, when I went there, and met Carol and probably a few other new people, I was interviewed by the press, trying to explain what made sense to me, but obviously didn't make any sense to them. They just looked at me blankly when I said, "It's because she is disabled that you are saying this." They said, "Yeah." That was their point of view: yeah. I said, "No, no, no, no, no, you're confused." They didn't get it and I didn't know how to say it, either.

All of us learned through years of working on this issue, how to express it even. Still, it's very much an uphill battle, but that was my first exposure to it, as an issue. Then, I began to go to the committee meetings of the ACLU. We were really trying to talk to their board about what was wrong with what they were doing, and trying to figure out how to influence them. I was able to sit in meetings and listen to, especially Carol and some others, speak to this. There were writings about it. The *Disability Rag* covered the case extensively, and then some of the subsequent cases that developed over the late eighties, when Larry McAfee, David Rivlin, some of the others, men with quadriplegia who were ventilator users, said, "Pull my plug, I want to die or else get me out of this nursing home." Somehow, those became "right-to-

die" cases too, and nobody was talking about "get you out of the nursing home" and a number of them made it crystal clear that that was what they wanted. Give me liberty or give me death. And they got death, with the courts, the media, every player, right lockstep with the idea that that's what should happen. Only us, out there, trying to say, "Wait, this is not the deal here." A lot of people died. Think of all the cases that didn't make it into a public mode. As each happened, and the courts would say, "Oh yeah, their life is meaningless, and all the state interests in preserving life don't apply here. Therefore they can have their plug pulled." That would then change the law of that state, in terms of how health providers would proceed. We weren't trying to say, well, "People don't have some kind of right to refuse excessive unwanted treatment," but it has to be informed consent with all the options provided, at least, which wasn't happening.

Cowan: The support services weren't available.

Coleman: Right, the individuals were pretty much making it clear in every case what their issues were, for the most part. That was my first exposure to that. That was an event in 1985. And the other big thing was—

Cowan: We're at the end so I'll—

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Joining ADAPT demonstrations for accessible transportation, 1985; leading ADAPT in southern California

[Tape 2, Side B]

Cowan: Okay, we're going to continue now with the other big thing—

Coleman: The other big thing. Well, that fall, there was—at least I think it was in the fall—there was the conference of the California Association of the Physically Handicapped. I went to that conference and I had been reading in the *Disability Rag* about that group ADAPT, and they had a workshop.

Cowan: What does that stand for?

Coleman: At that time, it stood for American Disabled for Accessible Public Transit. I went to a workshop they did, and that workshop was put on by Wade Blank and Mel Conrardy, his accountant at Atlantis Community, which is a Denver based entity. They were talking about the fact that coming up shortly, the American Public Transit Association would be holding its annual convention in the Bonaventure Hotel in Los Angeles. They were going to be arguing against lifts on buses. That's the North American transit organization that had fought to—and succeeded—in overturning the 504 regulations for accessible buses being constructed beginning in 1979. That was the 504 regulation, originally, but it was wiped, by a combination of the transit industry, General Motors Corporation, which funded some litigation, and Ronald Reagan pulling the reg.

Cowan: You mean, wiped out, not just postponed?

Coleman: Wiped out.

Cowan: Wiped out?

Coleman: Wiped out. So, we were fighting—ADAPT was fighting beginning 1983 or so, taking the issue to the streets. There's a long history of ADAPT that you can get elsewhere. There's actually a book about it through *Ragged Edge* called "To Ride the Public Buses," which gives that history. I went to this workshop, and what they included was a videotape from the first ADAPT action in Washington D.C. in 1983—at least I think it was '83. That action included the police, in Washington D.C., being very brutal with people in wheelchairs, including throwing one person and their chair off a lift, in the up position, and down onto the concrete. It was awful. By the way, the D.C. cops didn't do that again—not like that.

But that video told me for the first time that we are a civil rights movement. What the authorities feel toward us is the same, in a way, the same as toward blacks in the black civil rights movement. They don't just pity us. They will behave like that toward us, when we fight for our right to accessible transportation. That was very important to me in seeing us as a movement and wanting to commit some of my energy to that.

However, I'm still an employee of the state, and what I did was that I went to the Sunday—I didn't even think of taking work time, this is me back then. I didn't think of

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taking work time, but I took my Sunday. At that point, Tom Olin had been in the Bay Area. I can't remember exactly when he moved to L.A. It was during 1985 sometime—maybe then. He had been in the Bay Area for a little while, and we had reconnected after years of not really, anything but a postcard once a year, or something. He might have even found me through my family in Michigan, cause that's where he's from. He had decided to get involved in the movement. He actually wanted to go to Brazil, having been in Brazil before, seeing a lot of people with disabilities living in poverty and not having technology, not even wheelchairs. He wanted to be part of the effort to get wheelchairs and other devices into the underdeveloped countries. But, he was going to stop by in Los Angeles and learn Spanish. That was the theory.

And so he came down, and we shared an apartment and got to this action at the Bonaventure of ADAPT on Sunday. On that day, I put myself in the doorway of the Bonaventure doing a blocking. You know, I was ready to get arrested. That was okay, I was ready to get arrested. But, I hadn't been to any of the meetings or trainings. I just went. I didn't know any more than just to do. So, I get myself in the doorway and it's the same doorway that included—I knew there were people there that I later recognized—Bob Kafka and Mike Auberger and others. Anyway, I put myself in the doorway, and the police came along, and they dragged me out of the doorway and put me over to the side. You know, wheeled my chair, forced it to the side. They didn't have those automatic locking systems they have now, so they could pull you against your drive belts and move you somewhere and then they put me there. I didn't go back. As soon as I had any training, I knew, as soon as they let go of your chair, then just go back where you were. I didn't know that then. I just sat there like they left me in this little group and I stayed, and I didn't get arrested.

Meanwhile, Tom had his camera, and he was very interested in the camera thing, which obviously later became a very big thing. Bob Kafka was arrested—he was handcuffed with his hands cuffed behind the chair, and he was put in this van. Tom got up to the window of the van and took a picture of Bob with his hands cuffed behind him. That picture he later cropped, so what you can see is the wheels, the hands, and the cuffs, pretty much, from the side view—*power* ful picture. We ended up putting it on a calendar. It was all over the place—that picture. That really set a direction for Tom. But, the next day, I went back to work. I didn't take off the week. After work, I went over to ADAPT hotel. Sometimes they were there, sometimes they

were still there at the action. It was a very serious and difficult action, and one of the most difficult, for at least two of the people were kept in the jail for like ten days. A long amount of time, or eight days—a long time, and had injuries from that. Then for the next—1986, the ADAPT actions were geographically distant, and it didn't occur to me to take vacation time and go.

Cowan: You were participating just as a drop-in.

Coleman: Yeah, drop-in. There was no chapter in L.A. There was no group meeting or anything like that. There were a couple of interested people, but that was it. Then, in April of '87, there was an action in Phoenix, and that was in driving distance. We actually had—Tom had a relative in Phoenix, so we could stay with them, instead of having the expense of the hotel. So, I decided then to take vacation time and go, and we did.

Cowan: You and Tom, or more?

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Coleman: Me and Tom. This is when ADAPT had like eighty people. It was very much the pariah of the movement. I already knew that's what I want to become a part of. They were small enough then, to have a lot of good quality mentoring and discussion time and group meetings to plan strategy and tactics.

My first arrest was in the first action, which was Sunday night. You would usually arrive Saturday, there'd be some kind of meetings. Sunday night, we went to their dinner event at a place called Rustler's Roost, a big restaurant, up a hill. Up a hill, and what we did, was basically people blocked their driveway. Chairs laying in driveways, stopping incoming traffic. You couldn't bring vehicles in—and a bunch of us were up at the restaurant, in the driveways and parking areas and doorways, whatever, just packing it in. I went there, by the way, in my three-piece suit. I did. At some point, I began wearing a two piece suit and an ADAPT t-shirt, as my normal garb for ADAPT actions. So, I was going in my lawyering mode. That's what I wanted to be. I was never afraid of getting—I never believed I would get fired. My boss knew what I was doing, and they thought it was great. There were just these particular supervisor individuals, but it was unrelated to their work anyway. In Phoenix, at the Rustler's Roost, with the women in their cocktail dresses and their high heels, which were usually not the transit officials, at that time—it was almost all men who were the actual transit officials, but they would bring family. And they were crawling up the side of the hill in the grass, trying to get to this fancy restaurant for their event, and they'd have to come past us, including the little girl that was Tom's cousin, who was seven years old in a wheelchair with CP—cutie-pie. They'd have to come by her, and by the time some of these people got to the restaurant, they were crying. They were so upset at what they were going through. Both from seeing us, and for dealing with the awkwardness of the situation. And then they arrested. The restaurant called and they got police, and we were arrested, and that was my first arrest.

Cowan: You were arrested?

Coleman: Yes, I was arrested, then.

Cowan: And taken to jail? And handcuffed?

Coleman: I think—no, they weren't handcuffing. I've never been handcuffed. No, they wouldn't be able to handcuff me with my arms behind me, in any way other than breaking them. It wouldn't

happen. I've always approached the police as, you're doing your job, I'm doing my job, I'm not going to fight you, but I'm not going to move. And I've not really had too much in the way of any rough experience with the police per se. I really try not to, because I feel, physically, like I could be fairly easily injured if any of them were unhappy with me in a big way.

I was arrested there, but I think they probably took us to a processing site in buses, I think they did, and then they released us that night late. The next day, we went back. We went to something else, and I think it was the day after that, that we were doing a bus block—an inaccessible bus blocking. Kind of targeting the city's buses in Phoenix. At that point, I was arrested again, and that arrest, they did take us to jail. That was one of my worst physical experiences of the arrest part because I was standing next to Frank Lozano of Texas, who is a blind man who had a cane, and the officer grabbed his cane, and pulled it away from him, across my back. And they were wrestling a bit, and it was

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pushing me down and I was scared I was going to get hurt, but luckily then Frank let go, cause the other guy wasn't going to let go, and lost his cane at that point. I think the guy even broke it.

Anyway, we were all taken in—about forty, forty-two of us, something like that—into the Durango jail. We were provided such PA assistance as we could get, by the trustees—some of the other regular general population inmates. At first we were kept there for like one night, and then we were moved to other facilities, and split by gender. There were probably about eight women, and I was the most—Stephanie wasn't with us at that point. Stephanie Thomas was not with us at that point. She had to stay, stay back in Texas for some reason. So, I was probably the most, perhaps, technically knowledgeable of the women there, and found myself kind of trying to facilitate the communications, and getting people what they needed and whatever. I didn't have any training in this though. I was just going along. I was pretty scared too, when they moved us to a second facility and split us. They took away our clothes too, and we had to wear jail clothes. It was pretty scary. I remember shedding a tear or two, and then kind of thinking, well, I better put my attention more on the other people that were with me. What they ended up doing is they separated the men, like I said. What they told us was that after about twenty-four more hours or so, they told us that Wade Blank was coming with a accessible van to pick us up, and that the men were already out. So we wanted to get ready to go, we could, and we believed it, and got out. And Wade met us there. One of the women had been very, very upset and called home, back in some other state, and they had called Wade, and it was all a very big stir. I didn't know all of that, but what he was being told was, you gotta come get the women out.

They didn't release the men, and they lied to us. Wade didn't realize that we'd been told that story, cause we were holding together except for that one person. We were going to do the solidarity thing. We were released. At that point, Wade had probably been up for forty-eight hours, and was really tired, but then the men were in fact still in. Three of them were pretty high level quads, and had been kept in solitary without getting adequate bathroom-related assistance, and it was getting very dangerous for them. It was necessary to figure out what to do. That was a chance where—I had a chance then, to get on the phone and be doing a lot of calling, to—we basically convened a press conference for calling local religious leaders, and some other players to come down with us, and call for the release of these men, in particular the ones that were being medically endangered.

Cowan: It wasn't a legal basis to demand their release?

Coleman: I don't think—we might not have had a lawyer. I think we were trying to get a lawyer.

Cowan: You were a lawyer.

Coleman: Not in Arizona, and I didn't know anything about criminal law, disability law, or any other. Lawyering is a specialty kind of a thing. I had no means of doing anything, nor a license that would qualify me to do anything. We were trying to get enough help, but we used the press conference as a means of compelling the release of the guy that was most in danger. While the press conference was going on, they let one guy out. The other two were refusing, I think, to leave without all of them being allowed to leave. They held tight in spite of the fact that they were somewhat at medical risk. We went through the

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rest of the week. It took until Friday. I remember sitting at the Durango jail outside at the pay phone. I was like on the phone constantly. Others were, I think, doing things too, but at that point I was being given a chance to do a lot of organizing.

I felt very empowered by that, by the role Wade was allowing me to take, in a situation where their usual leadership was locked up. There was a vacuum there that needed to be filled, and he said, "Go for it," and I did. I felt very empowered by that experience. I left Phoenix, and immediately said, "I'm going to get Southern California people to the next action," which was in San Francisco, at the end of the—in the fall. I remember we got nineteen people there. The organization allowed me many opportunities to be part of organizing work, trainings, relationship building, writing, whatever was needed. Basically it was, "Go to it, whatever you can do, we're not dictating anything."

Cowan: Did you found a chapter?

Coleman: Yeah, the ADAPT Southern California, and actually ended up—I did that until '89—ADAPT Southern California from '87 to '89. I remember getting, over time, over twenty thousand dollars in grants. I wrote grant proposals to the Liberty Hill Foundation and some of the other—you know, leftie foundations down there, in the area, and got funding to get people to the ADAPT protests. We got to the point of having regular monthly meetings, and I had incorporated. I did some of the steps needed. I think we might have gotten a fiscal sponsor. I can't remember if I got the 501C3. I might have, or we might have gotten a fiscal sponsor, but we were able to get the money. So, that was really an important learning experience.

Visiting ADAPT chapters and demonstrating crosscountry in 1989

Cowan: And it was close to the end of your job.

Coleman: Right. By then, I was deciding that I wanted to—there were several factors. I was still sharing an apartment, by then a house, sharing a house with Tom Olin, and we were within a couple miles of Carol Gill and Larry Voss, and we spent quite a bit of time together. We were getting to the point of leaving Los Angeles. There were a lot of reasons. You know, the big earthquake is coming. A lot of people thought that, and we hate the smog, and I'm on the road for three hours a day, inching along the interstates. It was terrible. I didn't see a way, on a practical level, I could not get enough income working for the disability organizations there, to pay my mortgage and my car insurance. It just wasn't going to work. The cost of living there was too high.

I basically began to think, okay, I want to do disability organizing. I don't think—besides, they don't need me here. They got fifty organizers here, or whatever activists. I'm not remotely

needed here, comparatively thinking, and I was working on passing the leadership of ADAPT Southern California to some other people that were involved, and it did survive a while, and it exists now, but there were some years when it didn't have too much going on. Tom, Carol, Larry, and me, settled on the idea of moving to Tennessee. Tom and I left first and traveled to ADAPT chapters all over the country for six months.

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Cowan: Had ADAPT changed its name by now? Or was it still—

Coleman: That was '89, still transportation.

Cowan: And why did you pick Tennessee?

Coleman: It was far enough South to be reasonably warm. It was in the South, where organizing was very much needed, and we had talked to Mark Johnson about that. He was one of the activist leaders in Atlanta. That was the only ADAPT type activity going on in the South. So, we knew we were needed. I mean, anybody would be needed there to help, who had some organizing experience in disability rights. So, that was another factor for Tennessee. Another factor was that the cost of living was quite low. Something that one could survive okay with limited income. And it was closer to family. With family in Michigan, for us, and for Carol and Larry it was Chicago. That's a one-day drive. You can get to your family in one day from there, so that made it seem very attractive. But I had just sold a house in California, and I had enough money to take six months.

We drove, actually what was happening then, was we drove to the action in Reno, Nevada, that was happening that spring, the spring of '89, and then we went on to Denver, spent some time there. Then there was a notification of a big court case, the ADAPT vs. U.S. Department of Transportation court case, having oral argument in the Third Circuit Court of Appeal. So, Babs Auberger and I sewed a flag, with stars on the flag shaped like an access symbol, and we rented three-pointed hats and such as that, and went off to Philadelphia for the oral argument in the case, with Tim Cook handling that. We camped out in front of the court overnight, and we marched and took over the Liberty Bell. All the stuff that was in that book, right? Marched and took over the Liberty Bell, and you know, were at the oral argument when Tim did such an incredible job, and that was a great experience. Small action—it wasn't a regular action—about forty people came, I think. Then, Tom and I went back and continued around—we visited family and visited ADAPT chapters.

We would sometimes stay, I remember—We fixed my van so it had a big storage compartment in the roof. It was a high top and all of it was storage. We were carrying everything we needed to make room on someone's living room floor and stay there, and we did that with a lot of people—old friends, Arkansas people that we knew back in the old and olden days, from our twenties, plus ADAPT chapter people. We stayed with Bob [Kafka] and Stephanie [Thomas] for probably about a month in Austin, Texas. We stayed quite a while. We went to Atlanta and stayed with Mark Johnson and his family and helped organize the Atlanta action in late '89.

Cowan: So you became a real activist from—sort of went from not being involved to—

Coleman: Yeah, this is my life.

Cowan: —bang, this is your life.

Coleman: This is my life, yes. This is what I'm going to do now. I now know what I'm going to do. I knew I wanted to be involved in the movement. That was it. It's necessary to take these skills and turn them to this useful—I mean, it was perfectly clear that I could make my best contribution by doing that. I didn't quite know what the direction of that

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would be, other than activism, because you know, there were a number of disabled lawyers out there, but I was the only one getting arrested back then. Other people had arguments to give, about why they shouldn't. Well, the bar never challenged me. I didn't ever think they would, either. You know? This is not called moral turpitude. Moral turpitude is the name of the thing if you're a bad person, they could disbar you. I was fully prepared if anyone ever challenged me, which they didn't, to explain the reason for having to do this. You know, by then, I had been arrested quite a few times, and by now it's around thirty-five-ish or so, times.

Cowan: Oh my gosh, that's really a lot.

Coleman: Right, I don't even—and like so many who had—I know people who have been arrested more than I have, because they've been involved longer, but a lot of us haven't kept count anymore. I'm very proud to have become part of that group. I never got arrested alone—it was always with the movement. I had a chance to do a lot of organizing, helping different groups, or learning from being mentored with many of these folks for those six months, and then settled in in Tennessee.

Some ADAPT history

Cowan: Sounds like all of these antiwar movement stuff, twenty years later—or not quite twenty years—but everyone getting arrested, and making change through active movements.

Coleman: Right, it was. Absolutely, it was. Well, you may want to, for your own process, to spend some time on the history of ADAPT. Basically, the organization started when people at Atlantis Community, which was a place where there were a lot of nursing home escapees, who got out of the nursing homes, because Wade Blank, former freedom rider, a white minister freedom rider, went and worked for a nursing home. He was hired by a nursing home—this is a subject of a movie called "When You Remember Me," starring Fred Savage and Kevin Spacey. Spacey plays Wade. They got out of the—they got a bunch of people out of the nursing home, but he was hired to go around town, find all the young people in nursing homes, and bring them to that specific nursing home.

[Tape 3, Side A]

Cowan: So, continue with the founding of ADAPT. Wade Blank in Atlantis—is that what you said?

Coleman: That was in Denver. Wade had gone to Denver after—he was also at Kent State. He was in the peace movement and the black civil rights movement. He went to Denver, possibly wanting to have a break. He went to work for this nursing home, and his duty was to go around all these nursing homes and get young people from those nursing homes, all into one nursing home, where they can be together, at least it would be better for them to have that. He did that, and then he began to say, what is the reason why these individuals are here? It dawned on him that there was a civil rights issue here, that was not, in nature, different from the other civil rights movement he's been a part of. So,

he got folks out and started Atlantis Community, a center that got away—actually, played around with the Medicaid system, and got home health money to provide PA services to the individuals that he got out. They would come to the center and they would basically be staff or volunteers of the center, working on organizing, and they started tackling the bus issue in '75. In '75, "I'm out of the nursing home, now I want to get around. Why can't I ride the bus?" So, they started that process way back then, and by eight years later, they called for a training institute, you know, convened the training institute that Mark Johnson came to, and Bob and Stephanie, others—and that was when they formed ADAPT in '83. And then ADAPT proceeded for the following seven years to do the transit thing until the ADA passed and then came back, in a way, full circle, because of the origins of people who got out of nursing homes.

Cowan: So, now they changed their name slightly.

Coleman: To American Disabled for Attendant Programs Today, and we wanted to keep the ADAPT name.

Cowan: And their focus changed too, from transportation to—

Coleman: Right, the national focus changed to the attendant service issue. That attendant service is our civil right. So that's what it still is now.

Organizing in Tennessee; the Schoolhouse in Cumberland Furnace

Cowan: Well, if you'd like to continue on your explanation of how you got to Tennessee, and what you did when you got there. What did you have in mind?

Coleman: Well, what I had in mind was figuring out a way to do organizing. Another feature of Nashville, Tennessee, is that Nashville is within five hundred miles of half of the U.S. population, or was at that time. So, what that meant—I really wanted to be a traveling organizer, with Tom. We just wanted to use the van, drive out, assist people in organizing chapters, and find a way to get a grant to get paid to do that. That was the dream, to work out a way to that. But you know, in the immediate sense, I needed a job, so I went to work for the Protection and Advocacy Agency there, for a little while, in the Client Assistance Program.

Cowan: In Nashville?

Coleman: In Nashville, for about six months. I was terminated from that job. Basically there were problems there, and what I believe now is that what they wanted me to do with the customers that we had, was to turn some of them down, as not good cases. I didn't feel like I, for one, I wanted to do that; but for two, I didn't feel that I had adequate guidelines. That was my first disability position, other than being a board member of WCIL, and I felt ill-equipped to make that decision without more guidance than I got. It turned out later that a lot of other people ended up having problems with same individual, and that individual was let go, by the board.

At that point, I lost that job, and I was unemployed for a year. Luckily, I still had money left over from the house in L.A., so I did organizing for ADAPT for a year. I mean, I was already trying to start that, but it gave me a lot of time to do that. Even I had already, during my client assistance program, with the P&A job, been able to meet the disability advocates—a lot of

them, statewide, traveling on the job to Chattanooga, to Knoxville, to Memphis.

Cowan: How did you make contact? Did you go to local—

Coleman: Right, local centers for independent living. Well, there were a couple of them. And then other organizations, you know, just various organizations. And P&A itself had offices in each of those locations, or most of those locations. We were able to connect with people that way. It was a good opportunity to become introduced to the community, and I applied for grants, from the DD [Developmental Disabilities] council, especially. That was where a lot of money was then. They were favoring things that related to advocacy, but they ended up always giving their money, at that time, to certain nondisabled people. There wasn't a bunch of money going to disabled people at that point. There was later, but during the time that I was applying, none of those grants ever panned out. I also tried some of the foundations in the area that I thought might help.

After a year, in a rental house—and during that time, Carol and Larry reached the conclusion that they could return to the climate in Chicago, which is really where they wanted to be—Tom and I still stayed there, and after a year, I located a school building. I was looking for housing in the country—I wanted to buy a place before the rest of my house money from L.A. had been spent out. So, we started looking, and found a school building for sale, in Cumberland Furnace, Tennessee. It was a five-thousand-square-foot school building, built as a youth project in the fifties—early fifties, I think. It was spectacular, as far as the quality of—the inspector said this is going to stand another hundred years, this building will—this was built to last. It was built of wood. Some of the wood was so hard by then, it was like petrified wood. Just spectacular place, to me, but completely dilapidated. Nobody wanted it which was lucky. I took about a month to think about it because the plumbing was shot, it had no heat, it had nothing. It was hard, to even think about living in it, and getting it fixed. But, I decided to do that.

Cowan: For what reason? To live there?

Coleman: Well, to live there. I planned to live in a third of it, and find the money to convert the rest into a disability retreat and training center. That was my dream. It could actually—it had an auditorium, a stage, it had four classrooms, and two offices. My intent was to convert two classrooms and one office into the living quarters, which I did do, and still keep trying to get these grants, and find a way to fund the conversion of the rest—where one classroom could become a dormitory. These are big classrooms—twelve-foot ceilings, thirty by twenty-two feet. You know, it could've worked. Then there was a tool and laundry area, and all that, and the auditorium could be the training component. It was really exciting. It was on three acres, in a very, very rural tobacco farm territory, Tennessee. I just loved it. I was able to buy the place outright, for very cheap, and I was able to get a mortgage to fix it. I was able to install plumbing, and—

Cowan: Heat.

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Coleman: Yeah, heat was good. It needed it. Just get it into functional enough condition. Actually in the first eight months, perhaps, it didn't have a bathroom. So, we built a—dug a hole in the ground, and had a tent over the hole in the ground. That was what we did. Usually, I think we just ended up going to, in the wintertime, to borrow showers from friends, and in the summertime, we could shower outside. It was like a solar shower, I can't remember. Oh, no, we ran a hose. We

ran a hose out from the running water and showered outside, and we had to have a kerosene heater in the tent in the winter for the outhouse. Oh, it was wild times.

Cowan: Did Tom recall his days on commune?

Coleman: Oh, yeah. We had both had enough experience with having none of the conveniences that we could do that, all of the many long steps. We didn't have a general contractor, we had pretty much contracted with each kind of, you know, construction type of—the roofer, the dry waller, the floor refinisher, the plumber, the tiler, to get it all into condition. By the end, I had a sixteen-by-seven-foot bathroom with a roll-in shower, and thirty-six-inch-wide doorways, everywhere. I could freely move in that place without running into a wall anytime. It was great, not like my current apartment. That was the plan, to stay there and try to do that. None of my grant efforts ever worked out. I incorporated it as the Schoolhouse, Inc., and got a 501C3, and actually, I did get little grants—four thousand from the Appalachian Community Fund to do organizing work, but nothing of the magnitude needed to do more than a bit of the advocacy on top of my job.

Cowan: Not to make enough to make it a real retreat.

Coleman: Well, twice, maybe, we had people stay there. In '92, we convened those of us who had been very worried about the assisted suicide, euthanasia issue—convened a gathering at the schoolhouse. Carol Gill and Larry Voss came, Lucy Gwin from Mouth Magazine, Eleanor Smith, who is the Concrete Change person. That's what she's known for now, you know, visitability, but she was involved in the McAfee case in the eighties. Eleanor Smith came, and quite a number of other people—Jean Stewart, you would perhaps know.

Cowan: And that was before Not Dead Yet was founded.

Coleman: Oh yes.

Cowan: But it was coming.

Coleman: Oh, very much so. I mean Kevorkian was two years into it at that point, and being portrayed as a hero in the media. We felt we needed to meet and compare notes and start thinking about what can we do. We basically had two days of just group discussion about the situation. We came up with a few ideas and just really reinforced each other's concern and the importance of doing what we could. I know we took notes, and I could probably find them someday, but I don't think we reached any kind of a firm conclusion about how. You know, what exactly should happen—Maybe at that point, there was a little bit of a thought that there should be an organization, but there was nobody sitting in that room who was saying, "Oh, I'll go do that!" Most of us had some kind of idea what that could mean, and we were like "I'll write that article that I was saying—"

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Cowan: "And you start the organization." [laughs]

Coleman: It was very reinforcing to be together and to talk about how worried we were about how fast things were moving and how threatened we felt, and to begin at least thinking about more collaboration together in addressing this. I would say that our communication rate did step up on it, and our activity level. But then, we didn't really get to do that again. It was nice to have a schoolhouse where it was big enough. It was in summertime, the weather was good enough, and people could just sleep in the auditorium or whatever was needed. I did that once with ADAPT,

too. There was a Tennessee ADAPT get together. Possibly people were on their way to D.C., but we were all able to stop there, and fill the auditorium with cots or whatever, sleeping bags, and people could spread out and manage. It was really nice to have that capacity.

The Technology Access Center in Nashville, 1991-1996: long-term care policy and access to computers

Cowan: How long were you able to hang in there?

Coleman: I stayed there until '96, when I came here. Around '92, Tom got an invitation to do some filming—photo work in Denver at—I think it was a big celebration of an award being presented, because of the pioneering work that had been done on the transit issue there. I think it might have been either the mayor or the governor, and they were dedicating a big plaque. He ended up staying there in Denver. He likes to kind of move, I think, every seven years or so. It was about that time, so the transition took place. The last four years I was in Tennessee, I was there at the schoolhouse on my own and continued working in the technology—I did get a job in '91 at the assistive technology center, there.

Cowan: What was that? Tell me about that organization.

Coleman: There was an organization called—how could I—

Cowan: Technology Access Center in Nashville, Tennessee?

Coleman: Yes, that's it. It starts with Technology Access Center in Nashville, Tennessee, yes. How could I forget that after how much it has meant to me, which it has. There I was able to—they had gotten a grant to be part of the Tech Act [Technology Related Assistance for Individuals with Disabilities Act]. As you may be aware, there was a federal act that funded each state to develop technology-related projects to enable people to better get the technology they needed. The center got a grant, and the director there hired me and an OT [occupational therapist] to do the components of that grant, each of us part-time. That gradually grew, until over time I became the codirector of the center. A lot of my work was financial, while more of my codirector's work was programmatic.

Cowan: What sorts of the assistive technology were they providing? Are you speaking in terms of computer technology?

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Coleman: Technology-related services in general. That meant pretty much the services were assessments, demonstrations of equipment, a little bit of lending, and assistance in trying to navigate a system to get it purchased, work on IEPs [individualized education program], you know, with the education system, with the voc rehab [vocational rehabilitation] system, with health insurance or otherwise. I tended to do that part—the how to navigate the financial system, the rights-related system to get your services.

Cowan: Wheelchair?

Coleman: Yeah. Mainly, well, not wheelchair. A wheelchair is medical enough that they'll buy it for you. But, you know, what we used to say, if you can't walk, you can get a wheelchair. So, if you can't talk, you should be able to get a augmentative communication device, but the insurance

companies don't look at it that way. They say, if you're not going to a doctor to talk about your medical condition, then it's not a "medical necessity." Well, you don't have to be riding your wheelchair to the doctor to have that be a necessity, what's the matter with these people? Well, you know, we were constantly working on these kind of topics. I was doing individual customer work there, as well as doing financial things.

Eventually I became the policy analyst for the Tech Project under contract with the state. That's what expanded my hours. About sixty percent of my time was under contract with the state, but working out of the center to do policy work. There, I got to be involved in a long-term care battle, in my job, not to mention still doing ADAPT. So, I could go to a long-term care meeting with Medicaid officials, and as long as I put technology in there, I could put PA [personal assistance] services in there. My office didn't have a problem with me claiming that as work time which counted, because I was very conscientious in my jobs up through that job about giving them their due, in terms of work hours, and having my organizing time be extra, which meant I had very long days doing this.

Cowan: I can imagine. And you were still living at the Schoolhouse?

Coleman: Yes.

Cowan: This was commuting?

Coleman: Yes, so I was commuting. That was a little bit in and of itself. But it was a nice, beautiful country drive. I learned how to drive the windy roads and all that. I was able to do a lot of policy work, learn a lot about long-term care policy, from ADAPT people, from Bob Kafka, especially, and, from getting in there on a very local level and working with the different policy players there on the topic. At the same time, I was able to do individual customer work, advising people about the system they were dealing with, and helping them get oriented toward it. My work with the Client Assistance Program transferred to this too, because some people were trying to deal with the rehab agency, and I knew the rules there. So, it all added together to make it a good opportunity and the people I worked with were wonderful.

That center was a member of the Alliance for Technology Access, which was one of forty-three centers across the country at that time, that had started out mainly in education, but had branched out. A lot of computer technology, but primarily,

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alternative access to computers. It wasn't the computer per se, but it was whatever you could do with it, to make it work for that person. Either low vision or mobility access, and then there were training software programs that would help with people with learning issues, so that was very important in the augmentative communication. We had a speech pathologist on staff who helped do evaluations on speech technology. So, that was an exciting job, and I got to do that for, let's see, '91 to '96.

Cowan: Well—were you feeling like it was a big disappointment that a retreat hadn't gotten off the ground, and this was like going to be it now—you were going to be working for the technology center, or were you feeling like this is a transition job?

Coleman: I felt I did not know where things would lead. I did not stop trying to get grants, but I didn't put as much energy into that. I wasn't sure what would develop. I still expected, up until quite late in the time I was there, I still expected to retire there—to stay there in that house permanently. I made it for me to stay in. I wanted to live in the country. I hated living in the city, still do. I

am not a city person. I want to be in nature, but it was very taxing to spend that kind of time on the road. It was a bit lonely. Yet, I would've stayed there and kept on going, and if the grant came through, I'd you know, bid farewell to the tech job, but the tech job was a chance to do a lot of ADAPT things. I got to spend a lot of time on long-term care policy, and work with these chapters, you know, the new chapters of ADAPT that were forming, in Knoxville, and Memphis, and Chattanooga, and over in Little Rock, Arkansas, also.

An action in Bill Clinton's office in Little Rock, 1992

Coleman: When Bill Clinton was running for the primaries, I think it was back in '92—there was an action. He was proposing to cut PA services in Arkansas, and I had already visited some of the Arkansas people at the Little Rock center, where Richard Petty at that time was the director. Now, he's at ILRU [Independent Living Research Utilization Program]. We had met and we had talked, and I had met with other people there. They were very interested and then this threatened cut in PA services came down, and they said, "We've got to get over there to the capital, to the governor's office, Governor Bill Clinton, and do something." I basically consulted with them how to do such an action. They had eighteen people, they had some chains, and they had locks. They were going to go there, and you know, we talked about when you go in, what are you going to do? You're going to come up to the front desk, and they're going to say, you can't go in. Then what? "Well," I said, "Don't stop. In fact, don't stop at the front desk. Go as far in as you can before you're physically stopped, and then settle in." That is what they did, with a cell phone, a couple cell phones with them, and we were on the phone while some of it was happening. They got all the way into Bill Clinton's office. Inner inner inner office.

Cowan: Really!?

Coleman: Yes, with his desk and the inside bathroom and everything. The workers in the governor's offices totally taken by surprise. Eventually, they were able to get—well,

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they got a lot of attention, and the officials were able to reach Clinton, who at that time, I think was—he was in one of the big cities—Atlanta or New York, or somewhere.

Cowan: Campaigning.

Coleman: Campaigning, right. Actually the *New York Times* ended up carrying an article where he said he was going to restore that money. It was a dinky program anyway. It was less than a hundred people being served. There was no point to the state even fighting about it whatsoever, but it was very empowering to the group that they pulled it off. The next time they went for a meeting at the Governor's office for anything, they carried those chains with them and put them in the middle of the table and said, "We'd like to have a conversation now. Would you like to have it that way, too?" [laughter] So, they began to proceed with a whole different sense of their capacity to affect social change.

Cowan: That's wonderful.

Coleman: It was great, it's a wonderful story. It was such an honor, to be, by phone, part of what they did, what they did brilliantly. They were very, very effective at what they did, and that was what I got to do for a few years there. It was getting these groups the first technical assistance they needed, really, to get off the ground, and feel like they were connected to the national, because I was writing for ADAPT, I was, you know, working closely with Bob and Stephanie and others,

and Mark Johnson, and so by my being there with them, they felt connected to the larger group. I think that makes a big difference.

Cowan: Was the technology center itself adequately funded? Did they have problems keeping themselves going?

Coleman: The Tech Project provided some stable funding for several years, and they'd also had some other smaller grants, so I feel like my codirector was very effective at maintaining, although we never felt we had enough money, by a long shot. Not at all, but we were able to accomplish a good deal, and they have continued to grow, since I left. In fact, my codirector became the president of the board of the national Alliance for Technology Access. I don't know if he still is, but obviously they're a non-profit group. They rotate all that stuff. It was good.

Cowan: Sounds like a wonderful period of time for you.

Coleman: Yeah, I learned a lot, I learned about technology, I learned a lot more about the system. I also developed some management skills, and financial management of a small organization skills. They were beyond what I had gained from running a small advocacy entity.

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Thoughts on Tennessee experience and the ADA

[Tape 3, Side B]

Cowan: Well, Diane, do you want to sum up the value of your experience at the Technology Access Center before you moved on?

Coleman: I think it gave me a chance to learn a lot of things about operating, in a small disability service and advocacy organization. I particularly learned a lot about financial grant administration and budgeting, that included personnel and a wider array of costs than the copy and paper cost you have for an ADAPT chapter. There was quite a difference in an ADAPT chapter's finances to do that. And, I got a chance to do more direct customer work, where I learned some things that've been useful since—some of the personnel and administration kinds of issues, got a little more grant writing experience that was for a larger organization and a more mainstream environment by assisting others. I didn't actually lead on any of that. So I valued that, and very much valued the people there. It was hard to leave.

There, in Tennessee, I got to work with the aging community and the developmental disability community. They are, maybe, on a policy level with the government, at least, fifteen, twenty years behind. But that meant that the different disability leaders had every reason to come together, because most of the people there were very much aware of the developments on the federal level.

If you compare Tennessee and Illinois, while Tennessee had almost no in-home services for people with physical disabilities or older people, they had a much more developed system for developmental disability services. You couldn't have a group home that had more than eight beds in it. I come here to Illinois, and while they have open-ended entitlement to personal assistance for people with disabilities under sixty, and homemaker and some assistance for older people, the developmental disability system includes labeling a sixteen-bed facility a "group home." Here, the DD system is very behind what I experienced in Tennessee, in terms of the content of the rules, regulations, and approaches. I really feel—I'm not saying they don't

have some more progressive things as well, but supported living was much further along in Tennessee, than it is here, which means people who are eligible for a DD institution getting served in their own apartment, choosing their own roommate, et cetera—you don't get to have that here. They don't have supported living here yet, to any significant extent. Barely, barely, they're just starting to touch this thing, and they call it individual CILA [Community Independent Living Arrangement]. You almost can't get one.

Cowan: What could you attribute that discrepancy to?

Coleman: The power of the lobby group here, of course. It's always a lobby issue. Well, also, this is the national headquarters of the Voice of the Retarded, the archenemy of the de-institutionalization movement. Voice of the Retarded is the parents of people in institutions.

Cowan: And they don't want them?

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Coleman: Correct, and the union is funding them.

Cowan: Because they want those jobs?

Coleman: Correcto. It's a very serious problem.

Cowan: This is big issue, coming up, isn't it?

Coleman: It's a big issue. It's been a big issue. So, I learned a lot there, and a lot of that was transferred to my long term care related work here as well. I so admire the people that I got to work with. I got to work with the health care advocacy community. That was a huge issue. The Tennessee Health Care Campaign, and one of their major rights attorneys, who is a national figure, Gordon Bonnyman, they changed my life, as far as how ADAPT went down there. Gordon Bonnyman, who was just incredibly respected for his work by so many in the community there. When ADAPT arrived—when I arrived, you know, and started going to meetings there, and so forth, he had already told people there, when he saw the ADAPT action in Atlanta in '89, he had told people there, "We need an ADAPT here. That's what we need." And then I showed up, and then he said to everybody that was at all these tables, "This is good. This is not bad, this is good." He caused everybody to open the door and say, "Yeah, come into our meetings, come into our groups. We're going to at least be psychologically supportive, if not monetarily." I felt like I got to become part of that community in ways that meant a lot to me, and gave me a chance to learn so much more.

Before that, the disability stuff that was going on in California was completely segregated by category. The developmental disability, physical disability, and aging communities in California barely worked together at all. I don't know if that's changed, but there's so much turf, so many established entities out there. It was very difficult to work with all of that, effectively. There was a lot of entrenched disability power structure there. In Tennessee, it was like an open field. You could be—I could be very much more effective there in helping to build things, because they just hadn't had all those years of experience and development that California had.

Cowan: The ADA was being passed during this time, too?

Coleman: Right.

Cowan: That was affecting you down there?

Coleman: Well, in 1990, I had just been there a little while—and this was even before I bought the schoolhouse—was the spring action in D.C. I went there as an ADAPTer. I think I was able to bring some people from Tennessee, if I remember right. The crawl up the capitol steps was pretty infamous. It was on the news. And then we took over the Capitol of Rotunda and chanted. A hundred and four of us were arrested in the Rotunda, fighting to basically break the deadlock in the House [U.S. House of Representatives], and that is what happened. The deadlock did break. We were also trying to trying to deal with the efforts to weaken the transit provisions.

Cowan: And the deadlock was over what, for the record?

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Coleman: There were several deadlocks. Basically, the House wasn't moving the bill. They were trying to pass weakening amendments on transit, and on remedies especially. But we were able to, basically, make an impression. Within a couple months of that action, the law was actually signed. At that point, we knew we had prevailed on the issue of a lift on every new bus, and that's the only provision of that law that went into effect immediately.

Cowan: Is that right?

Coleman: Uh huh. Within thirty days of signing, on August 26th, every new public bus had to have a lift. No other provision of that law went into effect like that.

Cowan: And you attribute that to the action of—

Coleman: Oh yeah, there was no way that—why wait? And ADAPT wouldn't have accepted it. If we were going to say, "Okay, transit industry, you're all off the hook and we're going to go with this"—it wouldn't have been okay otherwise.

Cowan: You got that through?

Coleman: Yes.

Cowan: What did you think of the rest of the ADA? The definition seems to be causing some problems now.

Coleman: Oh, God, it's terrible. There's so many issues. But, at the time, though—not in the law. I don't see a problem in the law. The problem is with these players dealing with it, you know, courts and others. I'm not directly involved in it. I mean, I was involved in that fight in the sense that we write letters, do the usual thing, but I'm not personally focusing a lot of energy on that.

Cowan: So how did you wind up in Tennessee? I mean, wind up your stay there? What impetus made you leave that center?

Coleman: There were a few things that caused me to leave Tennessee. One, and probably the most important factor, was that my father was diagnosed with significant cancer, and I wanted to be near to my family then. In addition, I was pretty lonely out there, kind of isolated at the Schoolhouse, and there weren't a lot of people there from the movement that I could really have enough—the people I felt close to lived a little too far away. So that was wearing down on me a little bit. I had Carol and Larry in Chicago, and they had been encouraging me to apply for the job I now have. They were aware that there was an opportunity here, and they were encouraging that. I also had other friends, you know, in Michigan, that I saw at times, but Tennessee is pretty

far away. So, I was drawn by family and friends, and the fact that a job opening came up here that was workable—

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The assisted suicide issue, beginning of Not Dead Yet, 1996

Cowan: How about your interest in Not Dead Yet, and the assisted suicide issue? Was that drawing you away from Tennessee as well? Were you thinking there would be—or was that not really on the horizon?

Coleman: That wasn't really a factor. I could've done organizing anywhere, and I kind of thought I would go back to Tennessee—that I would find a way to get funded, and I would still be able to do that—but I needed a couple of years to be with family. I was actually hoping that I would maybe meet a disability activist who wanted to live in the country, and find another friend, or husband, companion, whatever—somebody to go do this work with, 'cause doing it alone is not nearly as rewarding.

As it turned out, as soon as I got here, practically, Carol Gill was invited to present testimony in Congress on the assisted suicide issue, because the two circuit court cases had been appealed up, and the U.S. Supreme Court had agreed to hear them. And so Congress wanted to hear about it. Well, Carol wasn't in a position to do travelling particularly, so she got permission that she and I could coauthor this testimony, and I would be the one to go to D.C. and deliver it. That was the plan. That testimony, which is available on our web site, was two-thirds, at least, written by Carol, and about one-third was written by me.

Now by then, there had been some discussion among some of us that, "Geez, we need to get a street group." There was no Not Dead Yet. The assisted suicide issue, this Kevorkian thing, and these court cases, is getting to the point—nobody is paying attention to our journal articles, our news articles, our disability press articles, our conference presentations, our court briefs that we filed in all these cases, etc, etc. It's not even making a dent. We have got to have a street group like ADAPT. That's getting to be evident that something is needed, and I don't know how far we had really gone. I had discussed this with Carol, and I had discussed it with Bob Kafka, a little bit. We had actually—ADAPT—had filed amicus briefs, as ADAPT, in some assisted suicide, euthanasia cases. They were kind of allowing me to sort of process that and get lawyers that would help write them, and we were working a little bit with the National Legal Center for the Medically Dependent and Disabled, at the time, on it. There was an organization called Life Worthy of Life in Atlanta still. There had been a possibility that that might fill that role, so we didn't really know what was going to develop.

At the same time that this congressional testimony was needed, April 29th, I think it was, Marca Bristo and the National Council on Disability convened a disability policy summit, in Dallas. I managed to get invited to it. I actually had a three-way trip. Fly to Dallas, then to D.C., then back to Chicago.

Cowan: Had you been hired here, at the Progress Center?

Coleman: Yes, I was. It was my third month now, I'm here three months.

Cowan: At PCIL?

Coleman: Right. We were in a slightly different location than we are now, but at the end of that year, 1996, I moved us here. I had become the executive director of Progress Center for Independent Living, that had been the subject of a "coup." The organization had gone through a consumer takeover "coup." Their former board and director were ousted, and they brought me in. The new board hired me to take over.

Cowan: So, you had just learned how to do, you've got the organization, and you're the head of it.

Coleman: Yes.

Cowan: Amazing.

Coleman: [laughs] Well, I had a really, really good board—a really supportive board with some very good people in it. So I was able to learn more of the ropes. I had a very good staff. The staff was in place, and their problem was with the former administration, not the organization. They themselves most of them were very much in tune with the philosophy of independent living, they knew what they were doing which helped, of course, tremendously. That enabled me to try to come up to speed, to get things taken care of. I was able to rely on the former fiscal person, who had been running the whole financial and contract side of the operation for years. I was able to learn from her before she decided to leave. She really liked the former people, but she hung in for about five months, which helped tremendously. So, I went off to this policy summit in Dallas in April 1996, to get back to the Not Dead Yet story. When I got there, I was going into the lobby area, kind of a registration table area, and Bob Kafka was sitting there. He was working on some piece of paper, and he looked up and saw me there and said, "I've got a name for your group!" Having a name for a street group is very important.

Cowan: Oh yes.

Coleman: Absolutely important. It was out of the Monty Python movie, and I didn't really understand. I didn't really remember the movie. "Not Dead Yet." Oh, my God. Oh, that's good. You know, had the right tone, to Jack Kevorkian, to anybody who was saying this was a good thing, "We're not dead yet. You will not get us. We are going to fight back."

Cowan: Great.

Coleman: To convey the message. Well, I called up Carol and I asked her if she thought that was the right name for this group, and I wanted her advice—if she thought it sounded good, or you know, she had been involved in it, and she was my introduction to the whole issue, ten years before. She thought it sounded like a pretty good name, so I went and I got a piece of paper. I had copies of my testimony, and little testimony summaries, you know. So I got a little piece of paper, and I wrote "Not Dead Yet," on it, and I made a little sign-up sheet. I started asking people—there were two hundred activists there from around the country—to sign on, to endorse the testimony. I would give them the summary to read—I had bunches of copies run at the hotel desk. I carried the sign around, and I carried my little sign-up sheet, and I gave people copies and asked them to sign. About forty people did, many of them on behalf of entities. Justin Dart signed on. The ARC [Association for Retarded Children] signed on, UCPA [United Cerebral Palsy

Association], at that time. I shouldn't even say that, cause they didn't stick with it, exactly. They stayed out of it later. But Allen Bergman signed on. Anyway, Bergman is the head of UCP, or

was at the time, or was the head of governmental affairs. I'm not exactly sure. Anyway, there were bunches of people there, and I had a chance to get a good number to sign on.

Cowan: To a group that really wasn't formed. It was still nebulous.

Coleman: Right, but they looked at that testimony, they read it, and they went, "Yeah, I'll sign that." They had a seven-page double-spaced summary. So, that weekend was over, and Monday I turned up at the Constitution Subcommittee at the House of Representatives, you know, of the Judiciary Committee, in the House, delivered the testimony—

Cowan: Oh, by yourself, so it wasn't you and Carol?

Coleman: Right, Carol couldn't go. That's why I had to go.

Cowan: I think it implies, on the online thing, that Carol was there as well.

Coleman: Oh, okay, she coauthored it, but she could not go. That's really the main reason I got involved in the testimony. It was a tremendous opportunity for her to share, because I wasn't invited. She was invited. But that fact that I got to do that gave me a credibility level with the people in Dallas. "I'm here, I'm on my way to testify in Congress." "Oh, I guess I better listen to you," whether they knew me or not. I mean, most of the people had met me through ADAPT over the years, that I talked to anyway. I mainly talked to people I had already encountered. I got a lot of sign-ons, went and delivered the testimony, including mentioning many of the people that did sign on.

Street theater protesting Dr. Kevorkian and an action at a bioethics conference, meeting Stephen Drake

Coleman: Then, shortly after that, the following month at the latest, there was an ADAPT action. The usual, you know, twice a year. I went to that. It was in, probably May, and talked to the people from ADAPT in Michigan, especially Bob Liston and Marcia Katz, who are now in Montana. We were all agreeing that, "Well, the first Not Dead Yet action should be at Kevorkian's house, shouldn't it?" Yes, that would be right, that would be really clear, so that's what we're going to do. We basically figured out when.

Oh, I know, they went back and researched a little and found out that in Lansing there was going to be a conference being held at one of the universities—at the university there. It was a conference about the ADA and medical ethics, and there were workshops about how maybe the ADA had gone too far in protecting people in the medical settings—stuff like that, you know? I can't remember the exact details, but it looked pretty good as a target. It had some bioethicists in it, and it had some average Joe people in the ethics hospital community. We felt that because of the titles of some of the workshops that it would be a good target. If we're going to bring some people together,

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we might as well get our money's worth out of such a travelling thing, so we'll hit Kevorkian, and then we'll hit the conference. By the word "hit," I mean do an action.

So, back in Chicago, getting ready for this, I ordered the first t-shirts from my friends in Tennessee. They knew a way that I could get them for real cheap—they were real cheap. The little green logo background on them didn't last too long. But we found a hotel, a cheapy hotel in Lansing, and we put out the word through the Internet a little bit. There was this guy up in

Syracuse University, getting his PhD in special ed who was one of the people who heard about this—an action coming up, this proposal—somebody was really good with the Internet, and it wasn't me at that point. The word got out, and he had gotten very concerned about the issue. His name is Steve Drake. He'd gotten very concerned about it—you met him earlier. He got very concerned about it, and he himself was brain-injured at birth, and had hydrocephalus, and the doctor tried to talk his family into leaving him in a corner to die on account of he would be a "vegetable," the doctor said. He finds the concept that a human being is a plant very offensive. Over the years, he had later acquired an interest in looking on the Internet on some of these topics and had particularly focused his attention on the words of the opposition. What does Hemlock Society write? What does the Canadian Right to Die Movement write? There had been the killing of Tracy Latimer, the girl with cerebral palsy, in Canada.

Cowan: And what was that about?

Coleman: A father who killed his twelve-year-old daughter, and the Right to Die Society there acted like that was all part of it. They weren't—in Canada they weren't hiding the connection between the so-called the Right to Die Movement, the assisted suicide movement, and the killing of a little girl. They found that all related somehow, and they weren't uncomfortable about the connection. Here in the United States, they pretty much tried to keep a great distance between the one kind of thing and the other kind of thing, as far as the media images go. He was reading about that and felt very lonely out there, until he saw this announcement on the Internet, "These people are going to go protest at Kevorkian's." So he found himself a train ride and a friend who lived in the Detroit area to stay with, and over he came.

That's how Steve Drake and I met. Now he's the only part-time paid staff person at Not Dead Yet, and is also my life partner. We met there. We got to the hotel, and I had my box of t-shirts—you know it was one of these big boxes. I was supposed to be taking care of quite a few things, and there were about forty people for the action. I had to figure out how to manage things, and he just came up and said, "Is there anything I can do to help?" "Oh, I need help with the t-shirt sales, and they cost ten dollars. Thank you." And he was so sweet. He carried that box pretty much the whole time. Selling t-shirts to anybody in our group who would buy them. It was great. He was so sweet. In addition—well, the first action, you know, we went to Kevorkian's, in a cottage that he was staying at. We pretty much snuck up on it. He wasn't there at the time, as it turned out. You can never do anything about that. We had people with signs, "KKK, Kevorkian Kills Krips," and many other signs about this whole topic. We had one guy from Ohio, dressed up as the grim reaper. He had red jello, melted jello. He and someone else laid down on the ground and poured red jello on themselves, or somebody poured red jello on them. It was just a lot of different bits of street theatre.

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Cowan: Did you get a lot of media attention?

Coleman: Some. We got an AP story with a photo. Local newspapers, and some local TV, I think. Tom Olin came, and he got some pictures—some good ones. Some people came from as far as like Denver. It was pretty well attended for the first time out. Some people had really been building their frustrations over this whole thing.

Cowan: So you got, sort of a national name then, that you hadn't had before, that helped.

Coleman: Right. Having the connection with ADAPT. The ADAPT Activists heard about it right then—I mean it was ADAPT people, in the beginning, especially from Michigan, who were helping with the organizing. Most of the people who came, were part of ADAPT, as well. Stephen wasn't though. He was just part of Syracuse University, and here I am. There were others too, who had not necessarily been connected to ADAPT, but saw this and wanted to be a part of this. Kevorkian had just been acquitted in April, just before Not Dead Yet formed. He had been acquitted for the assisted suicides of two women, middle-aged women, with non-terminal disabilities—one with MS and another with a kind of undiagnosed condition.

Cowan: I recall those cases. Those were his very first cases, weren't they?

Coleman: Yes, that was the third trial another letting him off, and after that there were not prosecutions for quite some time. There was actually in another county, but it immediately failed. The judge kind of ruled it out, and the prosecutor gave up. He felt that he would wreck his relationships in his little county, so—at least that's the impression that we had.

[Tape 4, Side A]

Cowan: So, if you can continue on the cases reviewed, not being prosecuted any further.

Coleman: Right, there had just been an acquittal in the third trial, and there weren't more trials brought for quite some time, against Kevorkian. That was part of the interest in going after Kevorkian, and seeing that it was necessary to step up the pace of activity at that point. So, we did that action on Friday, June 21, the first Not Dead Yet action, in Kevorkian's backyard. Got an associated press story and photo, and proceeded the next day, to go to the ethics conference.

We basically marched into the ethics conference, which was attended by probably sixty people—it was a small conference, relatively, but with some leading players in the ethics community. We basically went in chanting. I think we got partly down the hall in the building. We were in before they came out and said, "Uhhhh." I think they knew that we were coming. Some security guard had probably called. So they came out, and ended up in very short order, negotiating that we would be able to go and do a presentation to the conference. We figured out some specific parameters for that. We also were allowed to go in the first day, while the other people were presenting and Q and A [question and answer] them, when they were done with their presentations. When the woman presented about the ADA having gone too far in protecting people in medical environments, we were able to say a few words, and that similarly happened with other presenters. The people who were attending the conference were hospital

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ethics committee people, mainly. We asked them, "Well, how many of you have a disabled person on your ethics committee?" because basically they're deciding who lives and who dies, with disabilities. That's their "job," quote unquote. Only two of them out of the sixty or so raised their hands, as to having any arguable disability representation at all.

So, that night, we prepared our own panel presentation. We had Maria Matzik, a woman who is on a—she is in a horizontal position, lying down on like a stretcher, on a vent, all the time. She worked in the center for independent living in Ohio, at the time. She and her boyfriend were with us, and she was going to present because she had been through quite a bit in her time with hospitals saying, "We're not going to do anything for you, thank you very much." She was quite a lovely and articulate person who had plenty to say, and a really major story to tell these people. In addition, we had the Gloziers, Jim Glozier and Kyle Glozier. At that point, of course, Kyle is quite a bit younger, and they presented. Stephen developed a document

about the eugenics movement. He had studied that quite a bit, and written on it before, and he developed a two page handout, overnight.

Cowan: The eugenics movement, here in the United States?

Coleman: Yes, the United States one. That was among the handout materials that we provided to this conference, along with most of the things that were in our press packets. I'm trying to remember who all did present. There were a number of people, and it was empowering to do it. It was good to get that bioethics community. They had people from all over the country at it, so it was an opening salvo on them.

Cowan: Was it successful? Did you get feedback from them, that indicated their minds had been changed at all?

Coleman: I think some people's had. I'm trying to remember. It got written up in their ethics newsletter. They certainly struggled with it—tried to put some spins on it, but they had to cover it.

Cowan: Do you know if today, more ethics committees have people with disabilities on their committees?

Coleman: I'm pretty sure they don't, although I don't have statistics on it.

Cowan: It would be interesting to know though, if that had changed.

Coleman: Mmhmm. I don't think so. It's kind of funny. I was just telling people the other day—in the book, *Survival of the Fittest*, which is a novel, a mystery novel by Jonathan Kellerman, he writes about three pages about his profession—he's a psychologist—and their treatment of the eugenics movement and what it did. In the book, *Survival of the Fittest*, it's about a serial killer of people with intellectual disabilities. So, he's commenting on this whole issue of the eugenics movement and by the end of these three pages, he says "So, maybe our serial killer is a freelance bioethicist." And that about says it all. I'm not saying that all bioethicists are bad, but as a profession—not even a profession, because there's no real criteria. You can just call yourself that, right? What

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are they trying to do? They're trying to tell the health care system, what's the right way to allocate those resources based on the quality of—the characteristics of the recipient.

Cowan: Yes.

Coleman: It's by its nature, oppressive of people with disabilities, and it cannot help but be so.

Cowan: No, it can't.

Action at the Supreme Court, 1997, and media response to assisted suicide issues

Coleman: It was formed for that purpose. I don't see any other way to look at it. We deal with them quite a bit. That was the first action, and then following that, in fact at the next ADAPT action, Steve Gold and I were at the Democratic Party headquarters. They were dual actions, one at the Democratic and Republican headquarters. I think it might have been in D.C. Election time, '96—I can't remember what city it was in. Steve Gold and I are sitting in the corner. Steve is a disability rights lawyer. We were writing the amicus brief for the U.S. Supreme Court case, on

behalf of Not Dead Yet and ADAPT, which we nearly completed then and filed, shortly.

At the same time, by this time, Tom Olin was working with Lucy Gwin at *Mouth Magazine* in Rochester. They became very, very heavily involved in communication and organizing work for a rally at the Supreme Court, which was at the oral argument, at as yet, unknown date—a very hard thing to organize around. They made an incredible contribution and brought in Evan Kemp and Janine Kemp, and Justin [Dart], C. Everett Koop, many players that they were connecting with in one capacity or another. They did the most to enable that Supreme Court rally to take place. My role was paper development and some of the organizing around the hotel, and working with Robin Stephens, an activist in Denver, to facilitate a lot of that. Basically there were a lot of people, a lot of people involved in the organizing of it, but I do want to give credit to Lucy and Tom for being the core of making that happen.

Cowan: Do you recall what year that was?

Coleman: Yeah, the action was January 8th, '97. The organizing took place during the fall, and I can't remember exactly when we knew when that date was—the oral argument—but as soon as you know, then you pin it the rest of the way down. Amazingly enough, five hundred people made it to that action.

Cowan: Five hundred?

Coleman: Yes.

Cowan: That's stunning.

Coleman: It was stunning.

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Cowan: You were stunned?

Coleman: Oh, absolutely. We had about two hundred people at our hotel—one of the cheapest hotels you could possibly find in D.C. We were able to hold a training the night before, and there were about thirteen people speaking at the rally. It was very cold. Evan had had huge pink and black Not Dead Yet banners made up. It had been written up in *Mouth Magazine*, of course, in advance. That was one big way people found out about it. By then, the Internet was going strong. I think by then, Stephen had created a listserv to help get the word out. By the time the people who came on the train, and the bus loads from the nearby states—it was incredible. Hemlock Society had twenty-four people, I think it was, at their max, during the day. Little group out there. We had five hundred people. Across the street from the actual court, we had the sound equipment, which had also been provided by Evan, and Everett Koop spoke, Justin, many, excellent, excellent speakers spoke to this issue. There were, all in all, about seventy amicus briefs filed in that case—those two cases. It took about six more months till the actual decision came out. On the day of the protest, well the next day, there was a front page, color photo on *USA Today*, of the protest, with the banner showing—Not Dead Yet. It was spectacular. Needless to say, *USA Today* is on hotel floors all over the world, so that was it. Not Dead Yet exists. We are going to fight. This is what we are here for.

Oddly enough, or actually as it turns out, typically enough, from the standpoint of the *New York Times*, we do not exist. They were there. They were there, a reporter that someone said you need to talk to these people, and she turned and walked away from me. She was a few yards away from me, and she turned and walked away. When you read the *New York Times* coverage

of the Supreme Court cases the next day, not one word about the five hundred people. It was like we did not exist. The *New York Times* has been a really problematic player on the assisted suicide issue. They were having a lot of their writings on Kevorkian, done by a reporter—I'm blanking out his name [Jack Lessenberry]—

Cowan: You can put it in later.

Coleman: Yeah, I will. Lessenberry was actually quite close to Kevorkian and his attorney, Geoffrey Feiger, but not revealing this connection, which was later exposed by Mike Betzold in the *New Republic*. So, he was writing all these great things about Kevorkian, and the *New York Times* was printing it as fact, and really obscuring what was going on. There had been subsequent articles about, you know, "the selling of Dr. Death," how it was all engineered to get him in the mode where Barbara Walters thinks he, you know—I mean she profiled him a number of times, positively, and she's not the only one. Of course, Mike Wallace, similarly. They're very pro-Kevorkian, and it was terribly frustrating. I was involved in Tennessee, and I've been arrested in health care protests, not just ADAPT long term care, but health care system protests too, as part of larger groups of disabled and non-disabled people. To be a health care advocate and to see these alleged progressives, thinking that the same health care system that we're dealing with, that is perfectly ready to kill for money—this is not a surprise, perfectly ready to kill for money—we're going to give them the right to decide if our suicide is a good idea, and help us do it? We don't get the same chance to fail, sixteen out of seventeen is the chance, as other suicidal people. No, we're going to be assured that we don't botch our suicide attempt. And that is a good thing, they are saying. That is a good thing. Well, it's just unbelievable.

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Cowan: Not Dead Yet has never been invited to present an alternative—its own point of view, or its own opposition or argument against it?

Coleman: By whom?

Cowan: By anybody.

Coleman: Oh, by many. We do a lot of presentations.

Cowan: I meant, by the major media, programs such as Barbara Walters.

Coleman: Some, not by Barbara Walters, no. I think my first TV appearance on this topic was probably the McLaughlin Group, in the late eighties. But the day after the Supreme Court rally, I was on Nightline. I've been on ABC, World News Tonight, CNN, Court TV. During the Kevorkian trial, we were on Court TV a number of times, but it's a drop in the bucket.

Cowan: In some ways, having Kevorkian, because he was such a headline grabber, was an advantage because you got—it got media play. Now, how are you keeping your—

Coleman: Oh, there's still plenty of media play. I can give you this year's stack. It's like this. That's not even everything. Well, actually, that's a stack that includes action flyers, press releases, and some news clips. Ones that do enough mention to make it worth it. There's a lot going on still. It's very much an active issue, but yet, hearing you say that, reminds me—I mean you have to be paying attention all the time to see it. It's not going to be all that obvious.

The other thing is it's locality by locality. What we're trying to do is provide technical assistance as things crop up. A big part of Stephen's job is to be out there, noticing when something

happens. He's monitoring many places, where we'll be the first, hopefully to hear about the mother who killed her two sons in the Atlanta area, or there are quite a few murders going on these days. There was just a serial killer, a nursing home serial killer charged in Texas, where the reporters are obviously asking if it was a serial mercy killer. Well, that's not very likely. A serial killer is somebody—this serial killer figured out they could get away with it if they were in a nursing home. That's fairly bright, but not too surprising these days. They're not the first one to have come up with this idea.

Cowan: In this way, the internet serves you so well, because these would be so obscure.

Coleman: Yeah, we would be very unable to function without Internet access to each other.

Cowan: And what do you do when you hear something like that. When you hear about these brothers, what action does Not Dead Yet take?

Coleman: Call up our friends in Atlanta. Remember, we've been there plenty, in particular, I have, because of ADAPT. As you may recall, Eleanor Smith was one of the people at the Schoolhouse in 1992. Those folks down there worked on getting Larry McAfee out of his nursing home, so he could go on and have some more life after he won his "right to die" case. These are great people. They're great organizers. We're providing them some press materials, some, you know, a little editing support on some things they've written,

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just a sounding board for ideas about how to proceed. A few contacts and phone calls, and how can we help the different players to get them involved. They're going to be holding an action next week.

Cowan: Ah, so that would be the ultimate outcome.

Coleman: Right, and they've also had some things published already. So, it's like, become part of the media story. That's the advantage that Not Dead Yet has, probably over any other disability issue. From the standpoint of media, the issue is already in front of the media. Any of these things happen, it'll get covered. Reporters will be out there covering it. Then, we have to go there, we have to be there in a timely manner, with adequate materials, and a way of presenting our message. We've had now six years, back and forth with reporters and hearing their questions, and figuring out how to articulate the message in a way that functions. We've developed a lot of fact sheets and other kinds of materials that chapters can use. Each of the people involved in Not Dead Yet, throughout the country, they're very busy people. They're doing education, ADAPT, or other long-term care, or ADA advocacy, and on and on and on. They can't do monthly meetings, and for the most part no one is organizing a local ongoing chapter, but what they know is, for all those that have heard a presentation at a conference, or read the articles, they know we'll provide technical assistance when needed. If they will rise to the occasion at the time it happens, we can get our voice heard, because at least a lot of reporters have begun to recognize, no we're not the Pro-Life movement, no we're not the religious right, we're a different player. Some reporters are beginning to think, we might be a more legitimate player than anybody who's nondisabled. We might actually have the kind of stake in this, that they have to include, even if it's only one quote, they can't totally leave it out.

Cowan: And that'll make all the difference.

Coleman: In the end, it's making a difference. In fact, in the states where the issue has gone on the ballot, other than Oregon, where we were too little, too late, but other than that, we've been able,

through the activists in Michigan, California, Maine, Hawaii, so far, and a number of other states where it didn't make it quite as far, to hold the line.

Cowan: To feed the initiative.

Coleman: We've been able to keep it, keep it back, and be part of a broad coalition. This is even including low-income workers by the way, from the very radical, the non-unionized low-income worker movements—Western Services Workers have worked with us. Midwest Service Workers—these are folks that aren't even in the unions. They aren't getting their health care. They're gonna be very economically disadvantaged, usually minority, and the predominant forces in these groups, it was not rocket science to them to think, "I don't think we should be giving these medical players the opportunity to decide if my quality of life is too low, to justify—"

Cowan: My income.

Coleman: Right, well, after all, you know that this is supposed to be benign, right? The coalition has gotten broader and broader and the message has been able to get through. Really, I

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keep hoping that the press is going to ultimately see, and start telling the story of deadly medical abuses that are already going on.

Cowan: Well, don't you think it needs to be part of the whole story about medical care in this country?

Coleman: Yes, we do very much.

Cowan: What work are you still doing in long term care?

Coleman: Well, I'm on the State of Illinois Medicaid Advisory Committee, and it's Long Term Care Subcommittee. I still do work with the Chicago ADAPT chapter, but they're a very big strong chapter. They don't need me, particularly. I more benefit from working with them. I'm still involved because of being the director at a CIL, you know, wide variety of disability rights issue.

Cowan: How did you divide your time between the CIL and Not Dead Yet?

Coleman: Pretty much as needed.

Cowan: As needed?

Coleman: I'm juggling quite a few multitasks here.

Cowan: Sounds like you are.

Coleman: I think that the people on the board that took over the organization in late '95 before they hired me—I know that those who did know me said, "She's really good at multitasking." [laughing] That was a term that—I first heard it from them. Multi-tasking, they call it. So, I'm doing a lot of multitasking.

Significance of the work of Not Dead Yet

Cowan: When we talked on the phone, you said something like before '96, your career could have gone in many directions, but after that, everything led to Not Dead Yet.

Coleman: Right, I feel that the work with Not Dead Yet appears to be the most significant area in which I can contribute effectively to the overall disability rights movement. I have the technical expertise, both from my legal background, and the history of involvement in the issue. The fact that I was there starting with Bouvia with the people dealing with it, means I have just a build-up of historical knowledge of what has happened, and who said what when, and what did they write and do, and how were they misrepresenting what—how are our opponents changing their story as it goes along. That historical knowledge is useful. I've had a chance to work the issue a long time, and I have the capacity to operate an organization. Each of these areas is useful, and I'm turning fifty next year, so it's probably a good place to settle.

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It's not going to be over in my lifetime—dealing with this topic. If anything, the euthanasia movement is on a worldwide basis, getting more organized, and in some ways growing. There's also some growing opposition, growing organization within the disability community. We now have some international branches, a chapter in Sweden, some people doing things in the U.K. We very much feel that in the end, the disability movement, I hope, will include the anti-euthanasia issue, as part of the worldwide agenda that we share. I really do think that there is a growing international disability rights movement, where people with disabilities are feeling a sense of common history and experience, that on many levels does transcend the other cultural differences we experience. Not to minimize the significance of those, but I do think there are some very significant developments of community on a worldwide level, and I really hope that Not Dead Yet can be a part of that. I think that this can easily fill up the rest of my working time.

Disability culture: "Reinterpreting my life experience"

Cowan: Carol Gill often mentioned the words "the disability culture." Does that have meaning to you?

Coleman: Yes, definitely, in fact, our center has created a Dr. Carol Gill Disability Arts and Culture Award, as one of our annual awards presented at our liberty dinner banquet fundraiser. Yes, I do believe in disability culture. I think that's what I experienced in 1982, when I got to WCIL and I met all those people who said, "By the way, when you experienced, this, this, this, and this, I had that too." Everybody was able to put their notes together and was able to talk about those experiences at a depth that helped me reinterpret my life experience, and for me, that's the beginning of disability culture. I was able to shift toward an identity in which I am proud, not because of what I have achieved in spite of my disability, but of who I am, as a person with a disability. Because of my disability—that's why I'm proud. That is a huge conversion from how I was raised, and I think it's a lifelong—you never get over that stuff entirely. The shame of disability is the other side of it and the folks I got to be with, and still get to be with, and read the works of—Anne Finger would be another one to mention, by the way. Back in L.A., she was there then—Anne Finger. The struggle between shame and pride—to me, that's disability culture. That's part of it, a big issue.

The formation of identity is everything in changing how it feels to be in the world, and it means a lot to me. I want to foster it. I like the idea, by the way, of getting past people with disabilities, and being disabled people, because I don't see anybody going, "people who are women," "people who are lesbians," "people who are gay," "people who are black." No, they're going, "I am, first, my minority identity," and I want to be that too. I'm starting to go

interchangeable between the two. I don't want to offend anybody, but I'm very much in favor of being prideful.

Cowan: It's the politically correct expression at the moment.

Coleman: What is?

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Cowan: People with disabilities.

Coleman: Yes, in most places, but there is a beginning.

Cowan: We're at the end of this tape again.

Misrepresentations by the assisted suicide and euthanasia movements

[Tape 4, Side B]

Cowan: Do you have other thoughts, or further thoughts on health care in this country?

Coleman: Well, as I said, I was involved with the Tennessee Health Care Campaign, and I'm also on the board of the Illinois Campaign for Better Health Care, which are both involved in the national efforts to obtain universal health insurance, single payer health insurance. I absolutely believe that health care is a civil right and must be established as a basic right worldwide. Working on that topic, is at least a small part of my advocacy effort, and working with the many great individuals on it. I'm also trying to help them see in the assisted suicide and euthanasia issue, that those are not progressive social causes. That is not a progressive social cause. It's been sold to the public that way, that these doctors are merely deciding to relieve suffering when they do a passive or active euthanasia, but what I'm trying to say to people is that these doctors, these systems that are being developed, that could routinize medical killing. These are the same players, that are willing, now, as you see it, to kill for money. That is what the system is doing, and that is what managed care, in particular, has, I think, very clearly been doing—demonstrating the willingness of players to kill for money.

Cowan: By that, you mean that they will not provide services—

Coleman: Yes, you're right. It does need to be connected. The denial of health care, in order to save money, and resulting in death—I call that killing for money. The system is willing to do that. In fact, now, there are so many studies about Medicare, and basic services being denied, in spite of the deadly consequences. We should be shocked. We should not accept this. The assisted suicide and euthanasia movement in their more active forms—the Hemlock Society, the Death with Dignity National Center, the Compassion in Dying Group, are I think primarily fueled by the fear of disability, if you look at their writings, and their whole system is labeled "Death with Dignity." You ask them what is dignity and indignity, they start talking about disability as the indignity. That's what they're worried about. Many of their advocates have openly admitted that, and they don't see a problem with having that point of view about it, even though they don't have any first hand knowledge, or very little, other than maybe a relative's experience, which has perhaps caused them fear.

In addition to that, there is the medical system. That system is a part of the process. In fact, the medical system will be the alleged gatekeepers and safeguarders of people against any "abuses"

in assisted suicide and euthanasia. But those are the same people that would be permitted by these new laws, and are permitted in Oregon, to deliver

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lethal measures, active lethal measures to a person. These are the same people who are already denying necessary health care treatment in order to save money. How can we think that they are going to enforce safeguards?

Just in case people wonder, back in the eighties, before the U.S. Supreme Court established a clear, across the board right to refuse treatment—that is, basically no questions asked, now—before that right was put into that mode, there were all kinds of promises, about how the withholding of necessary medical treatment would only happen if the individual had made their own decision, in writing, with fully-informed consent, and all options provided. That is not what developed. What is now the case is that your relatives can do it to you. You can even be conscious and competent, but if you can't communicate good enough, or you have a brief lapse of consciousness due to some medical issue or drug, your relatives can sign off on denying you health treatment. You know, research shows how much they're influenced by whatever grim statements the doctor may wish to make. People are now already being denied treatment, being given their "right to die," without their real consent. Nobody sees a problem with that, or remembers what was being said in the eighties—all the promises that were made.

Cowan: The promise of options being provided—does that mean services provided?

Coleman: Well, yes, health care services.

Cowan: That was never done, was it?

Coleman: From what I can tell. Certainly, some people got their services, but the other thing that was really not brought into the picture adequately, was what about the social supports? We haven't even figured out that. Society still has very little clue what the disability community is talking to when we talk about social supports.

Cowan: What are you talking about when you say social supports?

Coleman: That would mean home- and community based services, and meaningful relationships, and opportunities for relationships, and other activities that the individual can enjoy, and respect—actual respect for who they are, not who they used to be, but who they are. We see all too little of that. Many people who acquire disabilities see that it's their former self who's valued, more than their new self. That's a very serious problem in our culture. So, the health care battle is very much a concern to us, and we hope that our allies in that battle will begin to take off the rose-colored glasses, begin to peel away the layers of misrepresentation of the assisted suicide and euthanasia issue, and see it for the very real danger it poses to everyone.

Some people might say, well, people with disabilities are the canary in the coal mine when it comes to the health care system. The main problem with that, or course, is the canaries are viewed as expendable, but we don't think so. That's the point of Not Dead Yet. We're not. I really thought that Justin Dart was doing a very wonderful thing in talking to the disability movement about leading humanity overall, and appreciating and realizing the best values that we can aspire to. I do think that the disability movement is, in fact, capable of providing a very important contribution—humanizing contribution, value-building contribution—to the world at large. Right now, we may be the most marginalized people who are the lowest on the social totem pole, but the truth is, a lot of

us have already dealt with the things that others are most afraid of, and we figured out how to do it. There is going to be this wave of aging society coming down the pike really soon, and the issues are the ones we have been at the vanguard of, and we know how to do this.

Cowan: Should the disability movement community lead the fight for universal health care?

Coleman: That's a possibility, but that's something that has to be done with everyone. We all need to come together. The one thing that we do need to be saying—we need to get various players who are currently talking sometimes about how one-third of the people take two-thirds of the money, and get them to stop saying that, because there's an implication or subtext behind that maybe we're getting more than we deserve. That's not just "people with disabilities," it's everyone.

Cowan: In terms of health care money.

Coleman: Right, health care money. I think that is the wrong way to think about allocation of health care resources. We need to get our allies to recognize that there's something wrong with that message, that you should be entitled to health care when you need it less, and not so much when you need it more. That's not right. That's not the system that they're actually trying to build, but people who are still making statements like that, need to understand that those are the wrong statements to make, if we intend to come together as a society, and provide health care for all on the appropriate basis. So, I really hope we'll end up working together on it, and just being a part of the public as we are.

Final thoughts: the need to protect basic rights for disabled people

Cowan: Well, I think we covered most of the things we intended to. Do you have other questions I haven't asked, or would you like to give some final thoughts to how far the disability movement, or the independent living movement, or the disability rights movement has come, and what remains to be done? A three-part question—I didn't really mean to do it that way. The disability rights movement—what's left to be done there, and do you view the last years as successful?

Coleman: I think the thing I've learned most from being in Not Dead Yet, and having a lot of dealings with the non-disability community over this issue, with a lot of the mainstream press over this issue, is that, for most of the things I do in disability, I'm communicating with people, including policy makers, who have a basic idea of what I'm talking about. They understand at a certain level, the terminology, the concepts, the systems, et cetera. Even when you're talking about the ADA with Congress people who disagree with you, you're still having a conversation. I think that what Not Dead Yet has shown me, is that most of the things that we're doing are on the margins of the mainstream. In Not Dead Yet, we discover more what people really feel about people with disabilities. I think in a somewhat more terrifying way, most people still believe, I think, that in a better world we would not exist. I think that, around the world, people with disabilities can still be tortured, incarcerated, and killed, mainly by medical people, without due process of law, and it will be seen as appropriate. Each of these things are happening in the United

States. People with cognitive disabilities are tortured in the facilities, as part of treatment plans. Obviously, people are incarcerated in institutions and nursing homes around the country, again, without due process of law, and people are being killed, starved to death even, without what I would call due process of law—without their consent. Yet, this is all considered legal and appropriate, in the U.S., and elsewhere.

Right now there's a beginning effort for developing a United Nations disability convention, a treaty that all nations would sign, establishing our basic rights. Now many people are talking about the rights to employment, housing, all the things that we work on in our daily lives, but there are a number of us—and I include Not Dead Yet in this—who would submit that you must first establish that we have the same rights as nondisabled people to not be tortured, incarcerated, or killed. We don't have that yet. We don't even have the idea that we have, in this and other societies around the world, the right to exist. I think we have a very long way to go, and the first thing is, of course, to reach ourselves. To empower ourselves to speak against all of the rights violations we face, to believe in ourselves, to reject the shame of disability that we're taught to feel, and to come together and join in the overall battle of humanity, and to take our rightful place in it—to make the contribution, a very big contribution that we have to make. But, I think things are actually probably going to get a lot worse before they get better. I hope that's not right, but when I see society, supporting Carol Carr, having murdered her two sons in a nursing home, and she's not the only one—there are many of these kinds of things going on right now that are gaining the sympathy of the public, the fact that that reaction happens tells me we have a very long way to go.

Cowan: Just for the record, you mean that the reaction was that it was okay for her to do it because the burden of her disabled sons had been so great.

Coleman: Right. She killed them in a nursing home. This is not the right thing to end on exactly, but maybe it is. I want people to ask themselves the question, when they ask that she not have any consequences for killing her two sons. How would they feel, if instead of relieving their suffering from the abusive nursing home, instead of killing them, she had killed the abusive nursing home personnel? How would they react to that? I don't think they would be nearly as sympathetic. In fact, they are saying that the lives of her two disabled sons, their murders did not deserve the equal protection of the law. They did not deserve the equal protection of the law.

I think that feeling is so prevalent that we have a very huge battle in front of us. In our daily lives, in independent living and otherwise, we're shielded from some of that, because we're operating in environments that are used to us.

Cowan: Are you complete?

Coleman: Yes.

Cowan: Thank you so much. This was a wonderful interview, Diane.

Coleman: Thank you for the chance to do this. It's an honor.

Disability Rights and Independent Living Movement Oral History Project

Carol J. Gill

Scholar and Advocate on Issues of Disability Culture, Health, and

Bioethics

**Interviews conducted
by Kathy Cowan
in 2002**

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

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Interview History—Carol Gill

As a seminal thinker and author on issues of disability culture, health, and ethics, Carol Gill brings an important perspective to the Disability Rights and Independent Living Movement oral history project. She is a leading figure in the development of disability studies nationally and at the University of Illinois, Chicago, which is the only such program in the country to grant a doctoral degree.

Ms. Gill became disabled after contracting polio at the age of five. Her interview describes her family and youth in Chicago, her experience with special education classes, and her early political awareness and evolving thoughts on the value of disability community and culture while attending a high school for "crippled children." She comments on the barriers she encountered while pursuing her education at Saint Xavier College and the University of Illinois, Champaign, where she achieved a PhD in psychology.

In 1976 she moved to Los Angeles, where she encountered the newly forming Westside Center for Independent Living, briefly taught at the University of Southern California in the disability studies program, and worked as a rehab psychologist and therapist to clients with disabilities. In 1990 she returned to Chicago, founding the Chicago Institute of Disability Research and joining the faculty of the University of Illinois at Chicago in the Department of Disability and Human Development. Her interview is particularly valuable in articulating her developing thoughts on disability identity and culture and for her consideration of the relationship of advocacy and academia, particularly in regard to her participation in Not Dead Yet, an activist group founded in 1996 to oppose the assisted suicide and euthanasia movement.

The interview took place in a daylong session in Ms. Gill's office at the University of Illinois at Chicago, with a short break for lunch. Ms. Gill has an excellent memory and spoke in detail and with enthusiasm about her life and interests. The transcript was audit-edited by the interviewer, and an electronic copy was sent to Ms. Gill who made necessary corrections and minor edits but no substantive changes.

Kathy Cowan
Interviewer/Editor
August 8, 2002

Family background in Chicago, impact of polio at age five, in 1954

[Interview 1: August 8, 2002] [Tape 1, Side A]

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Cowan: Carol, why don't we begin with something about your childhood, your parents' names and occupations.

Gill: My parents are—they are still alive—Mary Geraldine Gutt and my father is John Albert Gill. They were second generation United States citizens. Their parents were immigrants from Poland, both of them, and so my grandparents were always Polish speaking, pretty much exclusively. I wasn't able to communicate very well with them because my parents' children, none of us, learned how to speak Polish even though it was my parents' first language. They grew up in—especially my mother who grew up in Chicago—grew up in a Polish Chicago working-class neighborhood, and so very much spoke only Polish as she was growing up, went to a Polish Catholic school, and was very much in the Polish community. My father's community—he grew up in a small town in Wisconsin—was a lot more diverse; there were people from all different areas including Ireland and Germany and Poland and France. He grew up in Marinette, Wisconsin. Both of them were from very poor-working class families.

Cowan: Was there political commentary? Were they aware of or interested in community affairs?

Gill: Not really, and they weren't even, even though they both spoke Polish as their first language, were not all that interested in the country of their ancestry. Neither of them ever expressed a desire to visit Poland, to connect with their family there or anything, and pretty much embraced working-class American values, and had a certain skepticism toward authority that I think they conveyed to their children. I think that helped me out a lot in the future as I dealt with disability issues, particularly the medical system; my

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parents were not overwhelmed by physician opinion or direction. The doctors—I mean, I had polio—and the doctors that I went to, particularly orthopedic surgeons, were just notorious for recommending surgery after surgery, you know, "We'll take this muscle from there and transplant it here and tendons," and so on. My parents would hear this laundry list of surgeries that the doctors wanted to perform and would say, "No, I don't think so." And I was one of the few people I know with post-polio who, as children, had parents who vetoed suggestions for surgery. So I grew up relatively uncut compared to my friends who had polio who had multiple scars from surgeries.

Cowan: Were you sent somewhere for rehab?

Gill: Oh, that's an interesting question. I wasn't. I got polio during the big epidemics in 1954. And because we didn't have a lot of money, and I'm not even sure what the status was of our insurance coverage, I was sent to the Municipal Contagious Disease Hospital in the big polio ward in Chicago, a hospital that doesn't exist anymore. It used to be referred to affectionately as "Contagious." So I was sent to "Contagious," and I was in wards with mostly adults who had polio, but lots of kids too. I had the acute care in that setting and then I was transferred to another hospital for the physical exercise and all of that, that were to help me regain as much strength as I could. I was in the hospital for a total of nine months all together. It wasn't really a rehabilitation center that I was at but years later, after I had gone home and was functioning

as best I could and following my exercise regimen and so on, I think it was a coworker of my father who said, "You know, you should take her to Rehab Institute of Chicago and see if she could recover even more functioning." So my parents made an appointment and I went there.

I saw all the different doctors and therapists and had all of my muscle strength measured and mapped and all of that, and at the end of it, they delivered this horrible verdict to my parents, which was there wasn't much they could do for me so I wasn't an appropriate rehab candidate. I think my parents were just devastated because they always harbored this notion that I would, quote unquote, "get well." It was really hard for my parents to accept disability. So I have to say that part of my developmental context, part of my life growing up, was that my parents never accepted their daughter as disabled.

Cowan: They always thought you would get well?

Gill: They always hoped I would get well. They did everything they could to get me well or to bring back functioning in mostly my arms, because those were the weakest.

Cowan: Did they make allowances or did they expect your function to be, in your view, better than it was?

Gill: Make allowances in what way?

Cowan: In terms of not asking you to do some things that you might have been able to do.

Gill: You know, a lot of times when—I've noticed this in my own research—a lot of times people will say that parents overprotected their kids.

Cowan: I guess that's what I meant.

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Gill: Yes. And I've come to believe that what we call overprotection is really a pretty euphemistic reference, that what it is really is a lack of faith. And yes, my parents definitely had a lack of faith in my abilities. I think like everyone else, they thought that if I were disabled and if I were to be paralyzed, that I just was unable, that there were things I couldn't do. Although I have to say it was a pretty complex picture, because if I look back on it, I wasn't expected to be able to be, probably, a reciprocally giving member of the family. I wasn't expected to have the same duties or responsibilities as my brothers, for example, and yet, because it was therapeutic for me, I was given a dish towel and told that maybe I could dry the dishes. I was encouraged to do that and actually my allowance depended on chores like that. So in a way I was pushed, but in another way, the expectations were very low. It's that paradoxical set of expectations but lack of faith, or directives and pushing but lack of faith, that I think a lot of disabled kids experience. It's hard to figure that out as you're growing up.

Cowan: Yes. Well, I was going to ask you how you did figure it out while you were growing up, but first I wanted to ask you about your siblings. How many did you have, and how did this impact them?

Gill: I am the youngest child and I have two brothers who are older but they are true cohorts, they were twins. So my parents' first children were twin boys, non-identical, and that's how it was in their family for eight years essentially, and then I came along, and I'm the only other child. So there's a great difference in terms of, even the historical periods we were raised in, between my brothers and myself. Before I got polio, I was just this active little kid, and I tagged along

after them mercilessly. In fact, I don't know how they could stand it as much as they did. But I really saw myself from the beginning as part of an older group of kids, because they were so much older than I.

Cowan: You remember thinking that?

Gill: Oh yes. I couldn't understand why I couldn't just be in the clubhouse with them and—and, in fact, I did tag along and I learned an awful lot hanging around those older boys. [laughs]

Cowan: What was their reaction to your polio and your disability?

Gill: I have to reconstruct a lot by reading between the lines. My mother did a pretty amazing thing, I think, for those days. She stayed with me in the hospital and if she couldn't stay every night—and I'm telling you, she had to really push. She had to be one of those mothers from hell I'm sure, to be allowed to lie on a canvas cot in the room with her kid for almost nine months, not in the contagious hospital but thereafter. The days she couldn't do that, she had two sisters who took turns doing it for her, so it was just amazing support.

Cowan: It really is.

Gill: Yes. And I'm sure that my brothers must have really been affected by that. I'm sure that—I don't know what their relationship was with my mother directly—but, I'm sure indirectly they felt her lessened presence. Because she was a very traditional homemaker mother, had that dinner on the table every night, the cookies in the oven, and I'm sure that had to be interrupted if she was in the hospital that much with me.

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Cowan: But you never sensed any resentment on their part.

Gill: You know, I think that my brothers had good old healthy sibling resentment even before I got polio. They did. They let me tag along but I'm sure that they resented it. I remember feeling that they teased me a lot, and you know how children's teasing is, there's a negative hostile edge to it to be sure, and there was with them as well. One of my memories of my first days of getting the polio virus was lying on beds all the time, my head just killing me, telling my mother, "It really hurts, it really hurts, I can't get up," because I had meningitis essentially. And I remember my brothers saying, "Oh yes, she's got a headache, she can't get up." It's funny because that was the last big teasing about that that I ever heard. So I don't know if they had guilt or whatever older children feel, but I'm sure they had a combination of, looking back on it, probably guilt, resentment, and maybe jealousy over the time my parents spent and the focus of their attention.

But on the other hand, my brothers also had each other. They had constant company, constant companionship, and so they went through it together. They also became much more disengaged from me; I wasn't chasing after them now and my situation was very different from theirs, and we became pretty estranged, I think, in a lot of ways. They became detached, they went off. They were almost thirteen when I acquired polio, so they were ready to launch out into the world anyway, and they did.

Cowan: It was a major disturbance in your family.

Gill: Oh yes.

Cowan: How about your own feelings about it? Do you recall when you came to acknowledge to yourself that you had a disability? You were very young.

Gill: Yes, but I was pretty verbal and pretty with-it. I already knew my letters; in the hospital, at age five, I learned to read. So I mean I was—what you need psychologically to form ideas is pretty much words, and I had words, and I did a lot of thinking. I remember thinking about, you know, "What does this all mean?" I had no innate reaction of horror, concern or loss. It was more like, "Huh, those fingers worked yesterday and they don't work today, and they feel weird, okay. So what do you think I'm going to have for lunch? Are they going to make me eat carrots again?" That was more of concern, that sort of thing. I remember reflecting on that and thinking, "Everybody around me is either a doctor telling me I have to do something, usually painful, or therapists, or my parents looking really sad, but all I want to do is go home." To me, the disability itself was not the big deal; it was the disruption in my life and my relationships.

Cowan: So when you got home—how long totally before you got back home?

Gill: Nine months. It's pretty amazing in the age of managed care.

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Home teaching and attending school for children with physical disabilities

Cowan: Yes, nine months, that's correct; it wouldn't happen today, probably. When you got home, you had your life to resume and school, what happened then?

Gill: I hadn't been to school yet; there was no resumption. My parents didn't send me to preschool or kindergarten. We were living on the outskirts of Chicago in pretty undeveloped territory. When I grew up and I was still nondisabled, there were about three houses total on my side of the street. All the rest of it was what we called prairie here in Chicago, which is wild grasses and wildflower kind of meadows, so I had almost a semi-rural upbringing, really, right on the outskirts of Chicago. In those days parents weren't afraid of kidnappings and tortures and that kind of thing. So from the age of about two and a half, three, I'd get up in the morning, I'd go out and run with the kids, and my mother wouldn't know where I was, and I'd come home for meals; it was a very free kind of experience. So that's what I didn't go back to, it wasn't school, it was that.

Cowan: But school had to start soon after you got back.

Gill: It started in the hospital. I did get hospital teaching while I was there and I learned to read. Then I went home shortly before my six-year-old birthday and I was enrolled in school through home teaching, that fall, and so I had a year and a half of home teaching.

Cowan: Do you recall feelings about that? You wanted to go to school and had to stay home?

Gill: Oh yes, I wanted to do everything my brothers did. I wanted to go to the neighborhood Catholic school, but that was out of the question; I'm sure it was inaccessible, but also I was thought to be too fragile physically. I had been in the "iron lung—" that was the terminology—twice, initially when I got polio and then I had what everybody calls—it's interesting to revisit these terms—my relapse. I had a relapse, which I guess was pneumonia or something, after I had transferred to the more long-term hospital. It was pretty bad and I had a tracheotomy for the first time—an emergency tracheotomy, to help me breathe. Actually, they had to import an iron lung into this hospital; it didn't have them because it wasn't a polio ward. So I then had to be put back into the iron lung for a couple of months while I recovered from whatever this respiratory

infection was.

Cowan: So because of that they were thinking of you as frail.

Gill: Yes.

Cowan: But a teacher came to your house every day.

Gill: Not every day, I don't think, but whatever.

Cowan: And gave you assignments. Do you recall that teacher?

Gill: Oh yes, I loved it. It was great, I mean, what's not to like? She came and gave me all this individual attention, brought me things to read and color and keep myself active, because it was pretty boring recovering from polio all alone in my house. She

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complimented me a lot; she would encourage me a lot. She was the first of a whole string of school personnel who gave me very positive feedback about my abilities, my mental abilities.

Cowan: And do you regard that as a real early support for your independence?

Gill: Yes, I think so, I think for my sense of power. I think the message I was beginning to get was, "Okay, no matter what your parents and the doctor say about your inabilities, you have an area of power where you are excellent, better than other people."

Cowan: A significant influence, then.

Gill: Yes. That may not be the way I would have wanted to hear that message, that I'm better than other people, but it was a message that I was able to use to advantage.

Cowan: How long did that go on before you had other schools to go to?

Gill: I was on a home teaching routine for a year and a half, and then I transferred into the special school for my area, and that was Christopher Elementary School.

Cowan: And how did you feel about that? Was it a regular school or a school—?

Gill: No, it was a special school mostly for kids with physical disabilities. I wanted to go to the school that my brothers went to. I never wanted to be a nun, but I was a good Catholic girl and I wanted to go to Catholic school. See, here's an area where my parents would never have even considered that. I was very disabled. They couldn't even understand how I would ever not need them to take care of me, so how in the world could I make it in a school like that unless there were special people to take care of me. So they, without question, placed me in Christopher.

Cowan: Do you think they had an alternative? Could they have insisted on—was that possible?

Gill: I'm not sure. I mean, they still belong to the same parish and my father has been pushing and wheedling and cajoling the parish priests for several years now to just try to get a ramp up to the church, because he's afraid that when he dies, and he's eighty-six, that I won't even be able to attend his funeral mass.

Cowan: You mean now he's still, to this day—oh my gosh.

Gill: Yes, yes. So could they have gotten me in that school? I doubt it. But maybe if they were part of this new breed of parent that supports each other in those things they could have formed some

critical mass, who knows.

Cowan: What was your experience like at the special education school?

Gill: Oh, that was amazing! I was sent there supposedly because I was fragile, but here's the ordeal that confronted me and it was a physical ordeal. I had to get up and be ready to go on the bus at seven in the morning, so imagine what time I had to get up and get my braces on and all that stuff. At seven in the morning I was plunked on the bus. It just so happened that the way the route was constructed, that I was the first kid on the bus.

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Cowan: Were you in a chair or just braces and crutches?

Gill: No, I couldn't use crutches because my arms were too weak so I had to, you know, walking—I learned to walk. It really took a lot of energy. While my teachers were telling me how smart I was, my parents were my cheerleaders for how physically strong I was getting, and if I walked, I knew that it pleased them more than anything in the world, so I knocked myself out to learn to walk. And because my arms were weak, what walking meant for me is that I would walk and if anything knocked me over or tripped me or whatever, I would fall and I would fall with my full weight on my face or on the back of my head. I fell countless times and injured myself tremendously, but I walked. So, that's what I did.

Cowan: So you got there and you were walking.

Gill: No wheelchair.

Cowan: No wheelchair. Was it even suggested?

Gill: Oh, no. I didn't even hear about wheelchair use connected to me until, I think, I was about eight or nine years old. I had an aunt—my mother's one of many siblings and my father too—and one of my aunts was someone who lived in Connecticut or some other state and I didn't see her very often. But she came for a visit, so she had sort of a new perspective on our situation from afar. She looked at what was going on in my family and she said to my parents, "I'll buy her a wheelchair so that you guys can go out and do things, and you can go places and it won't be so tiring for her, and she won't fall." My parents said, "Thank you very much but no thank you." I remember my brothers and I were sitting in a room adjacent to where this conversation was taking place between my aunt and my parents, and one of my brothers said to the other, "She doesn't understand. Carol's not somebody who would use a wheelchair." And I took that in, "Okay, wheelchairs are bad. I can't use a wheelchair or I'll be a failure. I'm not one of those wheelchair people."

Cowan: So your identity as a disabled person was not—you were still thinking, "I'm different."

Gill: Oh, absolutely, and that's something that, once again, I think is really associated with polio. I've talked to so many people who had polio who said the family message for them is, "You're not like those crippled kids." That was what it was for me, and that's why I think my parents clung so long to the fantasy that this was just an illness and I'd get well, because if I got well, I wouldn't be a crippled kid.

Cowan: Back to your beginning in the special school, what other children were there?

Gill: That was really a revelation to me, because getting this message that I was not like all of those crippled kids, I really didn't even know who the crippled kids were until I got to that school. I kind of, I think, was looking forward to going to school finally, like my brothers did, even if it was a different school. But the bus deposited me, after two hours of riding around and picking up other kids, into this classroom, second grade, I was given a desk; it was terrifying. It was an old environment, you know, it had that patina of history on it and the desk even seemed antiquated and from another era, one of those wooden desks with the hinge tops. I sat there feeling really vulnerable and then I started

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to look around. I saw kids from every racial and ethnic and cultural background, and that was startling. But even more startling, I saw kids who were shaking and drooling, I saw kids who couldn't talk, I saw kids—the little girl next to me was writing with her feet; she had a pen in her feet and I noticed she didn't have arms, and I freaked. What was I doing here with all these freaky kids? It was horrifying for me. That was my first real confrontation with disability. I didn't know why I was there.

Cowan: Did you talk about it to your parents?

Gill: I doubt it, I don't think so. I don't think I did because I had already seen the sort of disparity between my parents and myself of our experience in the world. My parents were working people who worked with their hands. Neither of them graduated from high school, and so they really didn't have all that much experience with school. I think I also was very much reacting to this message I was getting that disability was a hot topic and almost taboo, that it was too emotionally loaded to really talk about freely.

Cowan: So you were there how much longer?

Gill: I attended special schools all the way through high school. I graduated from that elementary school and I went into Spalding High [Spalding High School for Crippled Children], because we were all funneled into only one high school for all of Chicago.

Cowan: How had your thinking changed by the time you left this school, Christopher Elementary?

Gill: Well, my thinking about my classmates began to change almost immediately when I got to know them and I saw the cool kids versus the not cool kids, the smart kids versus the not smart kids, and the fun kids. Then I almost immediately began to have friends, just very close friendships. I was, you know—I don't know how true this is of all kids with disabilities, but I was the best-friend type; I always had a best friend and then I had other friends that were pretty close, and a group of friends. So I had both a close friend—a best friend—and a group of friends that I belonged to, all the way through, and I feel very fortunate for that. I never felt alone.

Cowan: Were they all children who moved from school to school with you?

Gill: They moved, most of them, to Spalding, from Christopher. Some of them were on my bus and others I just saw in school.

Growing political awareness at high school for "crippled children"

Cowan: When you moved from Christopher to Spalding, do you feel you were like a different person, that your thinking had changed a lot, or were you then more identified in your mind as a person

with a disability?

Gill: Yes, I think I felt that I was one of the cool disabled kids that a lot of other kids didn't understand, a lot of adults didn't understand. Then when I went to high school that

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consciousness developed more and more sophistication until I began, like a lot of my classmates during that historical period, to connect our experience to the civil rights movement, and we began to use words like "prejudice;" we didn't use discrimination but we used prejudice. We didn't use the word disability so much in those days; it was either crippled or handicapped. So we said, "The world is prejudiced against handicapped people." I was able to articulate that with my friends' help by age fourteen.

[Tape 1, Side B]

Cowan: When you say, "this historical period," you're talking, about the civil rights movement beginning? You were aware of that, in your elementary years?

Gill: Not so much elementary but in high school, and the high school that we all attended was at the heart of the inner city.

Cowan: Is this Spalding?

Gill: Yes. I started in '62, I think. Yes.

Cowan: So what were you like as you started high school? What was going on? Were you still in braces?

Gill: Yes, I was walking and I had a leg brace and a back brace. It was a much bigger school. It was physically much more demanding because I had to change classes every hour and get to different parts of the school to attend art class versus math class versus English.

Cowan: This is still a special school?

Gill: Oh yes, and I should talk a little bit about the special school system of Chicago at that time.

Cowan: Please do.

Gill: It was mostly kids with physical disabilities who were directed into those schools by the medical system, but we also had kids who had sensory disabilities. It's funny because we were sort of Balkanized within the school; there was a deaf room for the deaf kids, where they got educated in sign language, and there was the EMH rooms for the kids with quote, unquote, "mental retardation," you know, Educable Mentally Handicapped. And then there were the TMH kids who we knew were, quote unquote, "worse," because they were only trainable, not educable. We generally didn't attend the same classes with them, or the deaf kids. We had some kids who were blind or had vision impairments, but I vaguely seem to recall that there were other schools for them and so we didn't have that many kids with those disabilities. So that's basically the way the students were organized. Most of the kids had physical disabilities because they were the ones who either didn't have some special school devoted to their impairment type or they were seen as unable to navigate the mainstream.

Which reminds me, disabled teachers is kind of an interesting topic. In elementary school, I don't remember any disabled teachers, but there were disabled secretarial staff.

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I remember having fun hanging around them and laughing with them and thinking, "Huh, a disabled adult, look at that," because that was my first experience with that, really, other than seeing beggars on the street or military veterans from World War II and the Korean War. Occasionally, you would see them on the street with missing limbs and they were kind of scary to me.

Cowan: Were you, as a group or just you by yourself, were you thinking that you should be in a mainstream school, another kind of school?

Gill: I never thought that I belonged there; I never thought I had an entitlement to that. That never occurred to me because I was, after all, unable to button my own coat and go to the bathroom by myself, even, so how could I be in a mainstream school? That's how that was framed for me and I bought it. High school had pretty much the same scattering of kids.

Cowan: High school was still Spalding?

Gill: High school was Spalding, all the way through. The teachers—this is really interesting—there was a teacher there who had polio who I believe attended Spalding himself as a kid, and that was fascinating to us, that someone who had a physical disability could be a teacher. But his physical disability was relatively unimpairing. He walked with a limp. I think he wore a small leg brace or something, but clearly he could do everything any other teacher did, and I think he even boasted of that. On the other hand, there was a teacher there my first year who used a wheelchair, and I was very impressed by her. Because here I am fighting the fight of the wheelchair, and here's a wonderful teacher who sits in a wheelchair, and she was from Britain. She was almost larger than life, what a romantic figure: a gray-haired, wonderfully articulate woman, who had a heart as big as the ocean and told us wonderful stories.

You know, this was the Cold War and during the Cuban missile crisis, all of us were still put on the bus and sent to school, but we were terrified that the atom bomb was going to drop while we were at school separated from our families. I was sitting in a class with her, with this teacher, and somebody dropped a book on the floor and it went boom, and everybody just jumped out of their seats. She looked at us and she chuckled and then she told us the story of living through the blitzkriegs in London and how if she could do that, we could get through this little missile crisis, and it was very comforting.

The sad story is that she was fired because she had a disability. Apparently she, like a lot of teachers in that school, ended up assigned there as substitute teachers, that just got there and stayed forever because there were no other teachers to fill those positions. And she, I guess, had lapsed into a very comfortable routine of seeing herself as a major teacher of English for the students and didn't think about her employment status until someone somewhere at the Board of Education traced her down and said, "Well, she cannot be a full-time teacher because she is physically incapable of that." The students—this was kind of my first taste of collective political action—the students wrote petitions and wrote letters of protest and offered to testify for her to the Board of Education, but to no avail; she was fired. We never saw her again.

Cowan: You think of her as a real mentor for you.

Gill: Oh yes, yes. I didn't have much of a relationship with her, I was just a freshman, but students who had been there a while had a wonderful relationship with her, and they just were devastated. It was so crazy. What kind of message was that to us about aspirations, career

aspirations? It was so arbitrary and we knew it. We knew it right away that this was a social construction of incompetence, that there was nothing incompetent about her, in fact, she was one of the best teachers ever in that school, but that it was a social decree.

Cowan: It sounds like your awareness of social and political reality was beginning to evolve then, between your thinking prejudice and discrimination and this example.

Gill: How could it not?

Cowan: Was anything else contributing to that? Were you aware of the other political situations in the country?

Gill: Oh, well, the civil rights movement certainly. I was going to school with a lot of African American students who were hearing a lot in their neighborhoods and at home, and they were importing that in, so we had those discussions a lot. The civil rights—some of the protests were taking place right in the city and we could see smoke from our windows from some of the rioting. So all that was happening. The women's movement was still not much of a blip, or the recent women's movement was not much of a blip on the radar screen. And then there was popular culture that supported our consciousness. I remember really clearly the movie *West Side Story* and that the message of wasteful devaluation of other groups, and marginalization and borders that shouldn't be there, exclusion, we took those lessons to heart. There were lots of performances in our school. We had an auditorium and we would have entertainment events, people coming in and performing for us: dancing, singing, comedy, whatever, once in a while, and the students themselves performing. I remember the song, "There's a Place for Us," being sung by the kids.

Cowan: From *West Side Story*.

Gill: Yes, from *West Side Story*, being sung in those formal kind of entertainment settings. I also remember a few times in the lunchroom at the end of the lunch period, when a lot of kids had already dispersed, but some remained in the cafeteria to socialize with each other, I remember groups of girls singing, "There is a Place for Us."

Evolving thoughts on disability culture and community

Cowan: You said when we talked earlier that your interest in disability culture and community was developing during this time. Can you say what you meant by that?

Gill: Well, I think the roots of it, I think that. My views of disability culture—

Cowan: What do you mean by disability culture?

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Gill: I think shared world view is mostly what it is, and also some elements of understanding and communication, such as humor. I think that there's a particular type of humor that people with disabilities tend to develop with each other when they're in each other's presence, that is pretty irreverent about authority and about standards that are handed down to us. I think that we develop humor that is turned at ourselves and our own struggles and limitations, and I think that we face some of the darkest—or what others who don't have disabilities would consider pretty dark and horrible realities, and we laugh at them. I think there is great power in being able to put the laugh to something that scares the shit out of other people.

I think there was that and certainly a way of looking at life through very different values than the majority culture had that resulted in our being shut away from mainstream society; we didn't embrace those values and we shared that with each other. That was the beginnings of my appreciation for being part of a minority culture and having a minority world view. I think the affective or the emotional component of it is that I really learned to love other disabled people during that period, and I loved the community and I loved it before I was even aware that I loved it. I had this strong sense of community that I took comfort from, that I learned self-validation from. My girlfriends relied on me just like I did them. They sought me out, they complimented me, I complimented them, we affirmed each other.

I drew on that when I began to think about what it is that has been rich about my life as a disabled person and what it is that made me realize that the cultural bigotry, the general cultural bigotry against disability, is a big lie; I knew it from that. I knew that if I felt so affirmed and so appreciative of other disabled people, affirmed by and appreciative of other disabled people, if I felt such a strong bond of connection and attraction, and that's important, that I actually relearned aesthetics, human aesthetics. I learned to value what others had been told is horrible. I knew that if I could do that, then there was something about this cultural difference that was valid.

Cowan: It was just probably approaching the end of high school that you were evolving these thoughts?

Gill: Yes, middle and end. I was a little younger than the other kids because the truth is, in elementary school, there were periods when I did get sick. I had respiratory illnesses and I missed a lot of school, and then I would make it up. I would come in and I'd get some kind of special attention from teachers who would fill me in on what I missed, and then I'd sort of forge ahead. I was dropping back and forging ahead, dropping back and forging ahead. Finally at some point they said, "Well, we are going to double promote you because not only do we want to make up the time you missed, because you are lapsing behind, but you have the capability of working a grade ahead." So they double promoted me and I was sixteen when I was a senior in high school, something like that. Although I was younger, this was a real formative experience to have when you were younger, to have these older kids talking about these things at a more sophisticated level.

Isn't that a theme? I just didn't realize it. When I was growing up, as a little kid my brothers were pushing the envelope for my awareness of the world because they were so much older, and in high school I still had the older kids, you know, helping me; I was tagging along.

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Choosing college

Cowan: Now as you are facing the end of high school, were you all also developing a sense of empowerment, entitlement, that you could go on to college?

Gill: Yes. Because I was part of this polio cohort and people with polio were seen very much as kids who had physical limitations but great mental capacity. I think that we were always getting these messages that, "You could overcome your disability by being smart and we will help you." Now it's funny because I've been recently talking to other Spalding alumni and they tell me that—most of them came a few years after me—they tell me that there was no longer an emphasis on college prep when they went through, that it had been lost in a matter of a few

years. But for my particular cohort, there was great emphasis put on pulling yourself up by your abilities and going out into the world and making it, and so they talked a lot with us about college.

Cowan: The teachers and all your friends?

Gill: Several teachers, I won't say all of them, because some of them were pretty discouraging. But a few of them really took an interest in us and pushed us and said, "We are going to hold you to high standards because the world will. You've got to make it." So we had a math and algebra teacher, and she also taught geometry, who was very, very tough. That would have been a good thing but she also made mistakes, which some of us caught her at, I mean, she wasn't the greatest teacher, but still the message that we should be held to high standards was a good one, I think. We had some English teachers and others who followed suit. I think, in general, I didn't get as good a high school education as people do in suburban school systems or private schools, and I was competing with those people, of course, when I tried to get into colleges and later graduate schools, and I think my education was deficient compared to them. But it wasn't as bad as we hear most special education is. I think I was there during the right time at the right place and we had teachers who did teach us.

Cowan: Well, how did you make your decision to go on to college?

Gill: I don't remember it ever being up for consideration. Obviously, I couldn't do what a woman is suppose to do; I couldn't get married and have children, and that's what women did in my family. They cooked, they had children, they took care of their house, and I couldn't do that, so I had to do what the guys did, which was go to college as my brothers did. It's interesting because my father is the oldest of nine children and I told you that neither of my parents finished high school, but my father very much valued education and was an undereducated but brilliant man, and was self-taught. He's the kind of guy who could get out a series of books from the library and teach himself a new profession; he had that capacity. He is a remarkable guy. He was remarkable in his accomplishments back then and his development. He, just parenthetically, when he was in his fifties and was contemplating preparing for retirement, he taught himself not only how to play the stock market by reading books but how to options trade, and became an options trader. It's pretty amazing for a guy with barely a high school education.

Cowan: Fabulous. Well, how did you decide what college to go to, what basis? You just knew you were going, for one thing.

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Gill: Everything was pretty much determined by what I would be able to do given my disability. I got very little—on the one hand there were teachers who encouraged me to go forward and said, "You're really smart and you should." But then there were the guidance counselors who were really lukewarm in their support of me and said, "Let's see what would be realistic for you. Maybe you can do proofreading or maybe something out of your home that you are going to be able to do." I remember thinking—oh, I know where I was going with the thing about my dad. His kids, his twin boys, my brothers, were the first kids in the family ever to go to college. And to this day, I think that my dad's children, all three of us are college grads, and I think we may be the only ones of all my cousins in that family. I think one became a nurse. So it certainly wasn't the trend. My father was not only giving me, but my brothers, this upwardly mobile kind of thing.

Cowan: A really strong influence.

Gill: Yes, I think so. And I don't really know what went into the decision that they would go to college but I think, again, they thought they had to do what my parents didn't have the advantages to do, and then I just thought I would do it too. The big issue for me was where to go to college. My brothers went to a private Catholic college in another state. Clearly I couldn't take care of myself, so I couldn't do that. A lot of the kids from my school went to U of I [University of Illinois at Urbana-Champaign], which was the model program for kids with physical disabilities at that time, with Tim Nugent down there and all that. But once again I was deemed too physically weak and unable to take care of myself, too dependent to go there, my parents thought, so no one dissuaded them from my high school. No one said, "Well, but she can get personal assistance;" nobody even mentioned it. It wasn't a concept in my family that you could pay somebody to do what my mother did as my mother, every day, helping me get dressed, bathed, et cetera.

Cowan: It wasn't just in your family. That wasn't a big concept in the world at that time, was it?

Gill: Isn't that horrible? I think that was one of the most tragic oversights of my whole developmental period, is that nobody taught me the concept, "personal assistance." I thought you just stayed with your family until they died and then who knows, you went to a nursing home or something. It was just horrible. The future was always a scary question mark for me. It was terrible.

Cowan: So none of the people at Spalding were thinking personal assistance? That just wasn't there as a concept?

Gill: No, not at all.

Saint Xavier College, 1966-1970: personal assistance and accessibility issues; influence of the sixties and close friends

Cowan: And this was what year, that you graduated from school?

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Gill: '66. So we thought, "Okay, think small, think local. Small Catholic college." There were about three girls' Catholic colleges in the area; I applied to all of them and I got accepted at all of them. One of them had a dorm, and in talking with the nuns at this school as I was preparing to go in, I think it was the nuns who raised the question about whether I didn't want to stay in the dorm. We said, "Well, how could I do that?" They said, "Well, we have a nursing school as part of our campus and maybe we can get one of the nursing students to help out and take care of her." So it was still very much the care kind of mentality. I don't think my parents were very excited about that but something, looking back on it, must have ignited in me and I thought, "Hey, the leap into adulthood, maybe I can do this."

Cowan: What school was this?

Gill: Saint Xavier College. So we embarked on an experiment: I was going to stay in the dorms and pay someone. Well, unfortunately, the person that the nuns chose to be my personal assistant, even though it wasn't called that, wasn't the right person. She really didn't know what she was getting into. She really wasn't willing to be a personal assistant. I guess she had thought, even

though she was told otherwise, that it would be a minimal commitment. I think it was the second night that I lived in the dorm, everybody on my floor got together and they were going to a baseball game, and I wanted to go too. It was sort of, like, for freshman. So I was included, and that went really well. I went to the ballgame and we had fun. When I got back to my room the lights were out—this person was actually my roommate, the person who was my personal assistant—and she was asleep. I woke her up to help me get into bed, and she was pissed. She didn't want that encroachment on her freedom.

So behind my back she complained to the nuns, the administration, and continued leaving me out of the loop, in terms of self-determination and decision making. The nuns just came and visited me and said I was no longer welcome in the dorms because I couldn't take care of myself. It was ridiculous. It was really incredible, and it was very hurtful. I think it probably set back my embrace of personal assistance quite a few years, because the message it sent me was, "Your needs are too great. Nobody can handle them except your mother," kind of thing. It was terrible.

Cowan: That's really undermining.

Gill: Oh, terrible, and also distorting of facts because little did I know from Berkeley to Champaign, people even with more limitations than mine were doing quite well with personal assistance.

Cowan: That's right. The concept was out there but hadn't come through yet.

Gill: Yes, hadn't come through to us.

Cowan: So what did you do then?

Gill: I had to leave, there were no two ways about it. There was no negotiation; they wouldn't try another person. And later on I made friends with people who would have been great personal assistants, but that window of opportunity was over, so I had to leave.

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Cowan: But you stayed in the school, you just didn't live on campus?

Gill: Yes. And so I had to commute and my mother had to drive me because there was no accessible transportation at that point either. We had the old Mayor Daly in power then and the buses were not accessible, and they weren't going to be made accessible.

Cowan: How about the campus, was it accessible in any way?

Gill: Yes, it was fairly newly built and it was flat. It was pretty much on a couple levels with elevators—it was no problem, the campus itself.

Cowan: And were there other people with disabilities on campus that you knew about?

Gill: There were a few. In fact, my first week in that dorm, there was another woman who I think also was a polio survivor, who was living in the dorm; I think she was a sophomore or a junior. She walked with Canadian crutches and she was politely, distantly friendly. I remember getting a sense from her that she was very much integrated into the nondisabled student body and that she wasn't exactly like me, but she could be nice and say hello and be charitable, but that was it, ships passing in the night.

Cowan: What are Canadian crutches?

Gill: As opposed to crutches that you lean your weight on, on sort of a resting place under your arm, the resting pads under your arm, these are the ones with the wrist cuffs where you put your weight on the handle under the wrist cuff, and usually they're metal.

Cowan: You were still walking in braces at this time?

Gill: I guess I should back up and tell you that around age fifteen, also in high school, I began to use a wheelchair part time at school, because I was just getting so tired. The doctors told my parents that—one doctor in particular, said that he thought my exhaustion from walking all day was contributing to my getting respiratory infections, and so we tried the wheelchair half a day and it really helped.

Cowan: An electric wheelchair?

Gill: Oh my, no. No, no, the old wooden and cane seat wheelchairs that somebody had to push you in. And I couldn't manually push myself in a manual chair, and power wheelchairs at that point were these exotic gadgets that only very, very rich kids had, so no. By college, I was using a manual wheelchair all day, to get to classes. The way I did that was I had to really develop my social skills and ask some nice young woman in each class if she would push me to the next class. So in a way I was just kind of this very vulnerable person relying on other people's largess, but at the same time learning the skills that I needed to negotiate those favors.

Cowan: What kind of response did you have from your professors?

Gill: Now, the school that I went to had a faculty of extremely politically progressive nuns, progressive in both pedagogy and politics; they are very well known for that. The instructors were a real mixed bag. I had these wonderfully progressive young nuns,

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who were tossing their habits off and becoming part of the world, and then we also had kind of outcast lay teachers that the nuns took in for political asylum. We had antiwar protesting faculty who had been dismissed from Columbia and places like that, and who were looking for a job and whose political values resonated with the faculty and administration at our school, and they were taken in. They were progressive liberal Catholics.

[Tape 2, Side A]

Gill: Most of the teachers that I had were pretty supportive. Again, I think they thought, "Well, she got this far, it must be her brains and we'll nurture that development, and I guess she'll do something in the world." Now we are into the late sixties and it was a really good historical period for me to be growing up in and developing my ideas. Because even though I had gotten a lot of discounting messages that we've talked about, the world around me, the larger world, was beginning to question some of these parameters that people were constrained to live within, whether those be constraints on sexual behavior or women's roles in the world, all of these things now were up for discussion and critique.

I think that that was not lost on me as a person who had been pushed to the margins. I think that it gave me hope, maybe that I couldn't always articulate, but it gave me a sense of hope that some of those restrictions, some of those expectations, could be changed and could become more ideal, and that there would be a place for me in the world that maybe hadn't yet been considered. We were on a new horizon here; I very much had that sense of this being the new frontier, you know, from the Kennedy years. I think I felt I could be part of a new frontier about

what people are capable of being and doing.

My instructors were also very idealistic and we all felt we didn't need to conform to the past views of what people who were different, or women, could do. I did get a lot of encouragement. I'm trying to think of individual teachers. Yes, there were teachers who were encouraging to me. I did well in my classes, I was on the dean's list all the time, I was considered one of the smart ones "despite my condition." There were a few other disabled kids who entered the school, in fact, more after me, and I'm wondering if that other woman in the dorm who seemed to be doing really well, who had a disability, and myself, were without realizing it at the time kind of proving to the faculty at my school that disabled girls could make it, and so maybe they were more encouraging of others after us.

Cowan: Did you have any experience of discrimination?

Gill: In that school, other than the horrible one about the dorm, which I would put into that framework of having been discriminated against, not really. I can't remember anything that stood out. I don't think I was given a great deal of accommodation. I always felt that I had to conform to what the procedures and rules were and so on.

Cowan: Were you interested in any political activities at this time; were you participating in any of those movements?

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Gill: As much as I had time to, in the fact that I was a commuter rather than someone in the dorms where a lot of that activity took place. But, among my friends, were women who cut sugar cane in Cuba and who lead our sort of chapter of the boycott against buying grapes, because of the treatment of the migrant farm workers and so on, and so I was exposed to a lot of that.

The other thing that was very formative for me was that a number of our professors were radical Catholic pacifists. A lot of them were communists, and I really began to be more exposed to socialism and some of the values of radical pacifism, and I was a radical pacifist at that time. I became a vegetarian and was extremely anti-violence.

Cowan: How about the disability movement, were you aware at all that there was something going on?

Gill: No, not a bit, not a bit. One of the things that I sort of also skipped over in high school that was extremely important to me was, not only did I have some teachers who were very supportive of my personal development, and a number of them who even affirmed some of the political sense we were developing who said, "Yes, it is prejudice, people are prejudiced against you; it's just not fair, it's so damn unjust." There were teachers like that. The other thing that happened to me is I became very close to a mentor, a woman who was two years older than I, and because I had been double promoted, she was a year ahead of me but two years older than I. She was African American and for some reason she took such a liking to me and adopted me. I think she thought that I really needed her because I was this vulnerable little lump of clay with a brain, and she just thought, "Okay," and I became her project.

She was also Catholic and our high school made available to us, once a year, an option of going on a retreat to a retreat house, all the Catholic girls in our high school. It's kind of strange and I don't even know how it came about, and looking back on it, I don't know who really made this happen, but every year a bunch of Catholic girls with disabilities from our high school went to this retreat house. My mentor, Joyce, was one of them, and that's where we cemented our relationship. We stayed up all night, and the heck with the Catholic activities,

we just got into talking to each other about being girls, about our dreams, our hopes, our values, our experiences, our troubles with our parents and all that, and we connected big time. She essentially said to me—she was so direct always; she taught me to be very emotionally direct—she said, "I like you. I think you're fun, I think you're smart, I'm very attracted to you," not sexually but socially, and she said, "I want to be your friend and I want us to do a lot of talking and thinking together." It was like "Wow!" I mean, can you imagine how mature that invitation was? What an incredible opportunity for me or any girl in high school.

Cowan: And you were fifteen.

Gill: I was fifteen years old and she was seventeen, and she was telling me how to be a woman and how to be in a womanly relationship. We began to write passionate letters about our ideals and beliefs to each other. I wish I had those letters because we wrote about brotherhood, we wrote about social justice, we wrote about all these things about diversity and marginalization of different people. She encouraged me to have a sense of justice about inclusion and difference that others couldn't shake. That relationship lasted—she graduated, she went to the U of I Champaign, and it bridged that difference:

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I was still in high school, she was in college, then I went to a small girl's Catholic college, she was in the big university, she was a psychology major, I was a psychology major. That was so important to me.

An interesting thing is that she was dating a guy who was one year ahead of her in our Spalding School and he was a white Protestant polio survivor, a very physically disabled guy and brilliant, and so a lot of her letters had to do with the difficulties of this interracial romance. She herself had heart trouble and had a non-mobility disability. That was probably the most formative relationship of my life. I have kept a lot of her letters that she wrote me from the university. It's sort of like, "Letters from Joyce at the University," and they are just incredible; she was so wise beyond her years and so nurturant, and she knew she was helping grow a disabled woman of tomorrow.

Cowan: So through your correspondence with her when she was at the university, were you starting then to be aware of disability movements or independence for people with disabilities?

Gill: Still not disability, but very much political, because she talked very, kind of obliquely, about race politics, but her boyfriend became a major campus antiwar radical and an anarchist, SDS, you know, Students for a Democratic Society; he went through various political affiliations. The sad part of my story here is that Joyce died very young while she was at the university and it was horrible for me, but her boyfriend took the project over and was determined to remain my mentor; we had a tremendous correspondence also. His name was Dean. This story gets really strange so bear with me.

Cowan: Okay.

Gill: It is kind of a testament to the smallness of the disability community, I mean, the closeness of it. Dean taught me a great deal about antiwar politics, about political thinking in general, and at one point he handed to me what he called his journal or diary, or something. What it was is—he was very creative—and what it was was a collection of poetry, personal narrative, political analysis, all together in this thing he called "Adrian's Bible." He chose that name as sort of alter ego, very deliberately, to reflect both masculine and feminine aspects of himself;

it was androgynous, it was an androgynous name. I kind of had a lot of admiration for him on some levels and a lot of resistance to some of his ideas. We were very different people so we sparred about ideas and so on. But when I read this thing it was startling. It just put a lightning bolt through me because much more than he ever did verbally, his writing told his experience of being a disabled man and the pain of his marginalization, sexually, socially, in terms of his roles, expectations, his dreams, his fettered dreams. It was achingly beautiful and true, and after I read that, after I read his thinking, his heart in that, I could never think of him the same way; he was my brother from that moment on.

So I think what that piece of writing did for me is it really made me connect not only to Dean but to the sense that we were part of a group, minority group, a collective, and I think that he was on the verge of disability rights. He was not connected to Ed Roberts, Judy Heumann, or any of the other people that we think of as leaders of the independent living or disability rights movement, but I think he was getting there. He was beginning to transpose his sense of civil rights justice to address issues of injustice he experienced

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as a disabled man. If he had been in Berkeley at the time he would have been history now, he would have been part of history.

Cowan: So it was in that way your awareness of disability rights was beginning to grow.

Gill: I think so. I think that it poised me for what was to come.

Cowan: But still no awareness of other movements actually happening at Berkeley or—

Gill: No, not at all, and I was not one of the people who even saw any footage on the news about the 504 sit-ins. I never saw that until—I guess the first time I saw it was when I saw "The Power of 504," the video, but I certainly heard about it.

Cowan: Why had you chosen psychology as your major?

Gill: I can tell you a real quick, funny story about that. That was simply because when I finally got to special school, you know, I finished my home schooling and got plunked into the special school system, there was this routine that every new student had to be put through a battery of psychological tests including IQ measurement. So I was pulled out of class one day, sent to the school psychologist's office, and that began three or four days of testing where I had to go to her office every day and be tested. Somewhere in the middle of all this testing, I became not the participant, but the observer. I looked around and said to her, "This is kind of interesting what you do. I think I could do this," and she said, "I think you could do it too. You're a very smart little girl. If you ever decide to do this just let me know. I'll tell you everything I know and I'll help you." So it connected, "Gee, maybe I can be a psychologist." I guess, even at that young age, I was thinking, "I'm being told so many things I can't do, maybe this is something I can do."

I have to admit that I started out thinking, "Maybe I'll be a psychologist," through the years of elementary and high school. I changed my mind a million times and wanted to be a scientist or teacher or many other things, but when I got into college and I looked at the array of majors, psychology beckoned to me, and I have never regretted it because it's a perfect match. I just stumbled onto it by having to go to the school psychologist's office, but it was a perfect match for me because it is such a wide-ranging, diverse field. It has rules of inquiry that you sort of apply to everything else, but it can take you into everything from animal behavior to human

behavior to the way organizations run, and the way people think and how they form their attitudes. Social psychology: how people develop cognitively, emotionally, sexually, all these things are just fascinating to me, and I think it's been a really good grounding for my ideas.

Graduate study in psychology at the University of Illinois, Chicago

Cowan: Perfect for you. So you leave Saint Xavier with your BA. Did you decide to go for an advanced degree?

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Gill: Yes, I wasn't ready to go look for a job, that's for sure, and the school thing was going pretty well so I—

Cowan: Had you looked for any jobs, had you tried to work as a student?

Gill: No, they weren't offered, but no one was. It was a liberal arts college pretty much for the most part, although it did offer some programs in education and nursing and other health professions. No, people mostly worked during the summers outside, and I didn't have any options that I knew of, so I went on to get a master's degree. I didn't do all that well getting—well, I didn't even apply to many graduate programs, to tell you the truth. Even though I did pretty well on my GREs considering the pretty low level high school education I had, and doing pretty well at a Catholic girls' school, I didn't even think of applying to a place like the Ivy League schools or any of the big schools, and I don't know if I would have gotten into them. I think I applied to the University of Chicago. I don't know if I applied anywhere else, I don't think I did, and I didn't get into the University of Chicago. I did get into the University of Illinois at Chicago, so I went there. It was local again; I didn't think I could yet make it at Champaign. Looking back on it, I think I could have, but I didn't then, and nobody else thought I could have either.

Cowan: What was your mobility at this stage?

Gill: I used a manual wheelchair most of the time.

Cowan: Personal assistance still wasn't in the picture?

Gill: No. Around the time, I think maybe my first year in graduate school, I did get a motorized wheelchair though, so I got a little bit of tech under me and that gave me a little bit more mobility, freedom. This was a really wonderful couple of years for me though, because a very cool thing happened regarding employment. I was not only admitted to the graduate program, which turned out—I didn't really know much about the program—but it turned out to be a really rigorous and wonderful program in many ways.

Cowan: Do you recall what years?

Gill: Yes, 1970 to—well, actually I had an interrupted graduate education; it was interrupted by a psychology internship because I specialized in clinical psychology and I went away on an internship. It was also interrupted by several years of spine surgery, but I finished my PhD in '79. I got my master's in '73 and my PhD in '79. They offered me a job as a teaching assistant. This is really sad and I'm almost embarrassed to admit this, but I wrote back that I didn't think I could do it. "I can't do that." And the head of the psychology department—oh, I said, "I can't do that, I'm disabled," and the head of the psychology department wrote back, "Yes, well, we'll deal with that; we'll address that. Let us know what you need, we're here to address these

things." It was amazing that he had the consciousness to do that and very lucky for me, because I did become a teaching assistant, a job that I held for three years, and it gave me a foundation in teaching that was invaluable later on.

Cowan: What kind of assistance did they give you?

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Gill: Not very much. They scheduled me to work with people whose classes were in areas that I could get to easily; that's basically it. They were just very straightforward, logical, practical arrangements, but nothing great. And, oh my goodness, my own education was just so hard because the library was partly inaccessible. I had to have a family member always go with me, and this was not the age of technology so if I wanted to look up something in a psychology journal, we had to pull heavy volumes of Psychological Abstracts off the shelf and go through page by page. I mean, what a difference it would have made if we had then what we have now in terms of the databases online and full text articles that you just download and all that. And then if I saw anything that was interesting, we'd have to get our quarters out and go to the photocopy machine, and it was the stinky, shiny photocopies; everything was so hard.

Cowan: What family member was usually with you?

Gill: Usually my mother; she was the person who drove me there. It must have been horribly tedious for her because she wasn't really involved in the subject of my search. She just basically took directions, you know, "Get this book, turn to page whatever, write this down." It must have been horrible for her, but she wanted me to graduate so she did it.

Cowan: What were your feelings about yourself now as a person with a disability?

Gill: I think still feeling like a person who didn't fit in because of my own deficits; I attributed my difficulties to my deficits and I internalized the responsibility for it. I knew that I didn't ask to be disabled, so in that sense I didn't blame myself or feel guilty, but I also felt that the external world had no responsibility to accommodate me. That's the message that I got everywhere, from the environmental structure of the university and the city, and the greater world where, you know, there were not curb-cuts yet really. There was no accessible transportation. The buildings on a fairly new campus were not very accessible to me. The thought that the university might have a responsibility to not only make its structures more accessible but to provide help, assistance, for me to get my education was just totally—I was not there. No one was there though, really.

Cowan: Were you part of a community of people with disabilities at this point at all?

Gill: From my special school, we all kept in touch with each other. We wrote to each other as we went to different colleges or did other things in our lives. Some people got married, they had children, we stayed in touch, we saw each other occasionally, but definitely I harbored that sense of community in connection with other disabled women especially.

Romances and relationships

Cowan: So you went on to an internship between your MA and your PhD and you went to California, tell me something about how that happened.

Gill: Well, that was really interesting. Before I went to California, though, I had these spine surgeries and I also—one thing we didn't cover was my own romantic life and the partners that I had.

Cowan: Let's cover that.

Gill: I got my first kiss in high school and it was really cool because I was still a freshman. The only other sort of romantic stuff—before I had my disability, I was a very precocious four-year-old, and I played doctor with the little boy across the street. We were two nondisabled kids and, we all did that, right? So luckily my disability came after a period where I had a lot of physical activity, independent exploration. That was the good part of living in this sort of rural thing where I ran free. I got a lot of living done in the world before I got disabled to the point—by the way, even though my parents may not have had a great deal of expectations for me after I got my disability, they were very open to my being pretty independent before. I was one of those kids who got up in the morning, got dressed, made my own breakfast, et cetera, when I was like three years old, and my mother encouraged that. One of my fondest memories of that period is that I actually did chores for the family. I went and did family grocery shopping at a little neighborhood store all on my own when I was five years old, before I got polio, so I was doing that kind of stuff.

After I became disabled I went to a couple summer camps, day camps, and I met—I remember one boy in particular—and had a little bit of a flirtatious thing that was, you know, one of those middle school things. What's interesting is even though I had a disability that ended up with my being limited in a lot of ways in terms of mobility, and even though I was stuck in a special school system, I was able to go through these rites of passage just about on time: playing doctor, having the little crush with the boy in camp and all that. First kiss in high school was a senior who was on my bus. Once again a really gracious, mature fellow, who said—I could just see, looking back on it, I didn't think about this at the time, but I could see his wheels turning and thinking, "She's a cute little kid, I'm going to give her a thrill, I'm going to give her a kiss the day I graduate," and he did. He was one of these guys who stood out among—there are people like this in the disability community who are just unnaturally mature. He was a real prize to get a first kiss from because even though he rode our bus to school, he had a car. He had a car with hand controls and that was not very common, and he used to be quite a man about town and even smoked a pipe. [laughter] I really landed a good one.

That was kind of it. I had another boyfriend in high school for a while, and people on my bus that we talked dirty with and flirted with and that kind of thing, and so I went through all that stuff. In the girl's Catholic college there was almost nothing in terms of dating or relationships, intimate relationships. But when I was at the university I reconnected with some of these guys that I didn't really hang out with in high school but I knew them, and they went on to colleges and universities and through mutual friends we just connected, and I became involved with a few people. Now, here's the real weird thing: one of the people was my girlfriend Joyce's boyfriend who survived her, Dean. Dean and Joyce had both remained friends with or forged friendships with some of the people from Spalding, the Spalding graduates who went to the University of Illinois at Champaign, after them, or at the same time they were there.

A lot of the time I talk about the disability community as my disability family, as one of my families, and here's a case where friends connecting to friends within the disability community led me into kind of an almost insular loop. I talked about Joyce, who was my mentor in high school, and she went to the University of Illinois at Champaign, and then her boyfriend Dean who was there as well and getting very involved in antiwar politics. Dean had a roommate at one point who was also a younger Spalding graduate and he was, I guess, a freshman at the time, and they roomed together. I think it was typical for disabled students often to room together, I guess for support and sharing tips, or maybe it was a segregation thing, I'm not sure. At any rate, to make a long story short, Dean's roommate is the man I'm married to now.

Cowan: Is that right?

Gill: So we networked with each other, yes, relationships. Now Larry, who I'm married to, Larry Voss, is someone that I knew kind of vaguely in high school. He was a year behind me because even though we are exactly the same age, remember I ended up going ahead. We weren't in a lot of classes together and I didn't know him very well, and we weren't on the same school bus, which was a major thing. If someone was on your bus, you got to know them because you chatted for a long time. All I know is that before she died, Joyce started to write me about this guy who was Dean's roommate, and she thought he was very smart and very witty and just a really great person. She wasn't telling me this to sort of whet my appetite to get to know him; it was just one of these things that she talked about in passing in the course of her letters—that she rode on a train from Champaign to Chicago with him and he just had her in stitches with his humor, or she thought he was a really nice guy with a lot of sensitivities. A little interesting quirk in the story is that, I guess, Dean became a friend and mentor to this young roommate of his, and one day Dean's sister was visiting him and Larry and the sister hit it off, and he married the sister, so he was married. I kind of knew him vaguely as this guy who was in my high school once, he went to Champaign, he got to know Joyce and Dean, and he ended up marrying Dean's sister, and that's all I knew.

Somewhere, I think right before I got my master's degree, Dean reintroduced me to Larry and said, "You guys should talk with each other." Larry's marriage was breaking up at this point, and he had a young child, and he pressed for and got custody of the baby when their marriage broke up. This was, when you think of the times, this was unprecedented stuff. This is before *Through the Looking Glass* where there was some institutional support, some organized support I should say, for parents with disabilities. And it was just kind of coincident with the women's movement emphasis on what should be a fluidity of roles between men and women, which he took very seriously and embraced a nurturing role as parent and helped raise his child. He didn't ask to be divorced and wasn't going to let this kid go easily, so he sued for custody and got it, and actually it turned out to be non-adversarial; his wife agreed to it. Soon I was reintroduced to Larry as this guy with a baby and that was a pretty charming thing.

Cowan: You were still at the University of Illinois at Chicago?

Gill: Yes. So I got to know him. These were the days of communes and free love and happiness and all this stuff, and through Larry I met some friends of his and for a while

I had a really good time with exploring relationships with a bunch of guys who kind of knew each other. We became sort of a posse. I don't know, I haven't seen the movie *Oceans Eleven* but, I guess, I kind of had the Julia Roberts role of the woman among all these guys who were interested in politics and interested in developing new roles for men, and it was kind of fun

exciting times.

Then I went away on internship. Well, first I had the surgery and then I got a little bit more functional. It was easier for me to move around after the surgeries, and then I went to California.

Cowan: And now were you aware of a disability rights movement?

Gill: We are getting there, believe it or not. Except as a personal issue or an issue between individuals and some vague notions of injustice done to disabled people as a collective, I had no exposure to the disability rights movement yet. But I'm taking you up to like 1974, '75, so we are just on the threshold. I went to California and that's where I learned about the independent living movement.

Internship in Los Angeles, marriage, 1976-1977

Cowan: And tell me where you went to California.

Gill: I went to Los Angeles. I went to work for what used to be the Los Angeles Psychiatric Service but is now the Didi Hirsch Community Mental Health Center.

Cowan: You were an intern.

Gill: Yes, I was a psychology intern. This was my real foray away from home. I guess I should back up and mention that when I was at the University of Illinois at Chicago, I did move out of my parents' house; it was a momentous thing. One of my friends at the university—and I became very close to a number of graduate students at the university and felt very valued and accepted by them. We just had some really good times talking sometimes in our graduate student offices at the university but occasionally doing things outside of the university. They became a really nice group of people for me.

Cowan: Did you have a personal assistant at this time?

Gill: No, not yet. After my surgeries I was chatting with one of my friends there once and she said—she was quite wealthy—she said, "You know, I'd like to go get a really neat apartment in one of those highrises by the lake. Are you in for it?" I said, "I can't afford that." She said, "My family's got enough money for both of us, just keep me company." I said, "How am I going to get dressed and do these things?" "I'll do it, I'll take care of it," and she did. So we lived for a year, against my parents' cautions and concerns because all they remembered about my ability to live on my own was that disastrous week in the dorms at Saint Xavier College. So off we went and I made it. By then I was engaged, kind of, to one of these guys that I got introduced to through Dean,

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and so he was also a support for me. I made it for that year and then I went on internship, and I had that as a model of how I could make it.

Cowan: It must have been very empowering.

Gill: Oh, very, scary but empowering enough that I went 2,000 miles away from home for my next experiment in independent living.

Cowan: Did you have trouble getting that job because of your disability?

Gill: No, because again, the times were kind of right. The Rehabilitation Act [Rehabilitation Act of 1973] had already come and gone and we were waiting for the regulations. And even though I didn't know anything about the Section 504 sit-ins, I think the world was becoming more aware of disabled people as a part of society, and I have to tell you that trying to find an internship exposed me to the whole range of attitudes. I had no trouble getting an internship because the positive range of the attitudes was very positive, all the way from some psychologists in Oregon who were so enthusiastic about my becoming their intern in their clinic that they were willing to completely retrofit their building so it would be comfortable for me using a wheelchair. I thought that was incredible.

The other end of the extreme were a few people who were heading internship programs in the Chicago area who were incredibly discriminatory and bigoted. One, the most bigoted response I'd ever gotten, was from an internship chair who said, after my interview with him, "Yes, you interview well, your credentials are great. There's no way in hell I would ever hire you though. You had polio and I know that polio causes brain damage, and I couldn't in all conscience hire someone with brain damage to work in such a responsible position."

Cowan: That's just shocking.

Gill: It was so shocking that it almost didn't even sting, it was so ridiculous.

Cowan: Were they allowed to ask you on your application if you had a disability?

Gill: Oh yes, that was always there.

Cowan: Can people do that today?

Gill: No, I mean that's optional information, certainly. Sometimes you see it as "Do you belong to a minority group? This is optional information." And certainly during job interviews it's not legal to ask questions about how you can do things with your disability, but I was asked those things. Asked! I was interrogated about those things, very skeptically, that I could do what I said I could do. Even more hurtful was the fact that the first faculty member at my graduate school that I worked for as a teaching assistant had left the university where I got my training and went to another university, and he became head on an internship program. And even though when I worked for him as a teaching assistant he always lauded my accomplishments and how helpful I was to him and how good I was in my job, when I applied for the internship he turned me down only, again, on the basis of disability. He said that—you know, what's even

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more ironic is that this guy I had actually gone to to write letters of recommendation for me to other internship programs, and he wrote glorious letters saying I'd be a great intern.

But when I applied to his program he turned me down and said that because I used a wheelchair, he really felt that it was possible that I couldn't get to an emergency in time if a client was having a problem in the in-patient setting, and that because of that, again in all conscience, he couldn't put me in that responsible position. And it never occurred to him or he didn't want it to occur to him that I probably was faster using a power wheelchair than most people would be on foot. That was very hurtful.

Cowan: How did it affect your sense of your capability? Was it damaging to your sense of your own worth in any way?

Gill: I think it was challenging to my sense of worth. I think I constantly had to review the facts and try to figure out if they were right that I couldn't cut it, that I couldn't make it. I think sometimes I was angry, sometimes I was hurt, sometimes I wondered if they were right, but it didn't stop me and I got enough positive feedback from other people that it kept me going. And then I always had my disability community that I would tell these things to and they would say, "Oh what shit! More of the same crap we take all the time!" They helped me frame it in a way that I didn't internalize it enough that it stopped me. I did take the internship in California [at the Didi Hirsch Community Mental Health Center] where it wasn't the most positive response or the most negative, it was the most matter of fact, you know, "We're hiring you on the basis of your credentials." "What about my disability?" "Well, we're going to have work on that and see what we need to do, but I'm sure we'll work it out," was their attitude, and that was perfect.

It was a good place and it had a great history, and it had the kind of programs I wanted to learn more about and practice in. That was just wonderful for me because interestingly enough—of course it drew interns from all over the country and there we were, this group of interns—I never hit it off with the women there, which is unusual because I made girlfriends really easily, but in that program I never did. I don't even to this day know why, it just might have been the particular personalities involved, or it might have been something about the California woman or something that I didn't fit in, but I made really good friends with the guys.

When I went away and I went on this big experiment across the country in self-determination and independent living, I made this little mental promise to myself that I'm not very proud of. But I think it's very common among disabled women so I'm putting it out here for other women and that is, I wanted to prove that I could date nondisabled men. Although I had a few friend-maybe-romantic relationships with guys in graduate school, I never really explored that very much. I needed to prove that I could be attractive, and sadly, I needed to prove that I had to be attractive by nondisabled people's standards, and that's sad; it is sad in a way. But I'll tell you it turned out really well, because I got it out of my system real fast. I dated only nondisabled people; I had some pretty interesting relationships.

I was physically threatened and abused by one man. Thankfully, nothing like rape or anything like that, but pretty bad. I went out with him and I was able to function,

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sometimes walking, sometimes using the wheelchair. On this particular date I had with him that was set up by a mutual friend of ours, I wasn't using my wheelchair. Part way through the date, he thought it would be really fun to just kind of push me off balance and catch me, and did that against my will a few times, to just do a power trip on me, a control trip, and show that he could control me and I was at his mercy. I don't know where I got this from, but I told him to take me home immediately, that I didn't want anything more to do with this. And he wanted to stay the night. I said, "No." I don't know where it came from again, but I was able to set limits, really emphatically, on things like that. I might have sometimes wondered if my deficits were in me and I didn't measure up, but there was a line that sometimes got crossed where I knew it wasn't me, it was them, and there was no way these guys, anybody, was going to go beyond that line for me, so I was able to set that line.

Cowan: Yes, that's a real growth. Do you think that's a common experience with disabled women who date nondisabled or even disabled men?

Gill: Well, the part of it where I think there's this sense that if you don't make it there you don't make it. I think that's all too common because we are so enculturated by nondisabled standards of

beauty and attractiveness and worth as women, so I think a lot of us are vulnerable to that, and I certainly was. But I think the part about the bottom line drawing, unfortunately, too few women have been given enough reinforcement of their strength to do that and I'm so grateful I was. I think the reason why we have such high rates of abuse for women with disabilities is certainly not their fault, it's because the abuse is all around them and it's going to fall on them. But maybe a few of them, if they just had been given enough encouragement to develop that bottom line, maybe there would be a few less instances of abuse, and to me that's really important to help women develop that. That's why I mention it.

On the other hand, I had some incredibly wonderful relationships; one became quite serious. That's a really high point in my life, not because he was nondisabled. As it turned out, having that year taught me that the guy being nondisabled was absolutely meaningless. What meant something is—I finally got to learn about what I wanted in men and it wasn't nondisability, it was depth and commitment and the capacity to love. I did find that in one or two of these guys and particularly one, but we went our separate ways; it didn't work out. But after that, I was finally ready for real relationships and to make decisions wisely. That's when Larry and I really found each other again and decided to—

Cowan: Did he come out to California too?

Gill: No, he didn't. He was there in Chicago. We ran up thousands of dollars worth of phone bills when we decided, "This is it." Then after my internship I went back and I just once again dove into this relationship full force and got to know what this relationship could mean to me, but also with his son because he was still raising this toddler. Then I became part of that little boy's life too, and we got married in 1979, right after my orals for my dissertation.

Cowan: It looks here like you were in California a long time though, through the Hirsch internship.

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Gill: Just one year.

Cowan: Oh, the Gateway Psychiatric Hospital?

Gill: That's after we married and we came back. This was quite a marriage because I had my orals, I think on a Friday, we got married on a Sunday, and Monday we moved 2,000 miles back to California where Larry had never been and trusted me that this was a good place. We very deliberately chose to have our married life begin in California because he then had just gotten his master's degree in special education—no, actually he had a year's experience as a teacher at that point. But we knew that we wanted to develop our careers without having to contend with ice and snow and an inaccessible city. I told him that access was better out there; there was an independent living movement out there, and so he said, "Yes, okay I'm up for it," and we moved. We packed that kid up and we moved, and I became stepmother and job aspirant and all this stuff. Larry very quickly found work in special education.

Cowan: Moving back a little bit into the Didi Hirsch experience, so it sounds like that was when you began to be aware of what was going on in California in terms of independent living and civil rights for people with disabilities. Do you think of them as the same or as separate movements?

Gill: Well, I consider one sort of as a subset of the other pretty much because I think disability rights is much broader and affects a much broader and diverse constituency. Independent living has the potential to be pretty meaningful to almost all people with disabilities because all of us, on

the basis of impairment, are unfairly infantilized and restricted, and independent living speaks to that. But I think that its origins and the way it plays out in a lot of settings is that people with physical disabilities sort of have priority. A lot of people with sensory disorders are getting supports and resources other places and don't think of independent living centers as their places, and certainly that's true with people with developmental disabilities and a lot of times people with psychological disabilities. I don't think it has to be that way, but that's what happens, is that, in too many places, independent living gets narrowly conceived as physical supports, or structural or programmatic supports for people with mobility disabilities. So I see the disability rights movement as broader.

First experience with independent living: Westside Center meeting, 1976

Cowan: Can you recall what your first experience with independent living was, the people or the place?

Gill: Clearly.

Cowan: Oh great, let's hear it.

Gill: I was at Didi Hirsch Community Mental Health Center and I was working in the day treatment center, which was for people with, quote unquote, "people with the most severe psychiatric disorders" who had probably been released from psychiatric

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hospitals and needed assistance and guidance to live in the community. So in a sense the day treatment center was providing some independent living counseling for those folks. One of my supervising staff counselors said, "You know, I know this occupational therapist friend of mine and she's been involved with a group who are starting a center, and they're going to have a meeting about it. You guys should get to know each other; you'd probably be really interested in this," and she got me invited to this planning meeting for the Westside Center for Independent Living in Los Angeles. I got to meet, that night, June Kailes and, I think, June Kailes' husband Bob. I think Doug Martin was there, if I'm not mistaken, I mean, it's kind of a little cloudy in my memory now. And a number of other people, I can't remember, Sandy Burnett was the occupational therapist that my friend knew about.

Cowan: So you were present while they were talking about forming it.

Gill: At a meeting! At a planning meeting, yes! Talking about Berkeley and saying, "You know, we can do this," and that kind of thing.

Cowan: What was your reaction? How did you feel?

Gill: I thought it was great that here was a very active and to me it seemed like a sophisticated group of disabled people. I was excited by it. I was, of course, very interested in the social possibilities because it was kind of lonely making it in the mainstream the way I was, with no other disabled people around. I thought it was probably something that I might want to get more involved in in the future if I moved back to California. I think I went to maybe two meetings and that was it. I sort of lost touch with the people. They were very busy and I was a new kid on the block. They didn't know me very well.

Cowan: What kinds of things were discussed at that meeting?

Gill: That I have less recollection of. I think some of it had to do with budget and funding.

Cowan: Probably not as thrilling.

Gill: Yes, that part wasn't so thrilling. It was a diverse group, though. I remember I didn't really have a ride home. I really flew by the seat of my pants. I had somebody drop me off and thought, "I'll get home somehow." I didn't live very far from where this meeting was and so I thought, "Oh, I'll talk somebody into driving me home." The person who drove me home was an African American man with maybe CP [Cerebral Palsy]; I don't know what his disability was. I don't remember his name and I don't think I ever saw him again, but he was nice. So he drove me home and that's about all I recall. It wasn't a fascinating meeting and I didn't grasp the whole connection with Section 504 and the Rehabilitation Act and these incredibly powerful activists in Berkeley. I didn't know that story, nobody had told me that yet, but I put it together piece by piece over the next years.

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Discrimination in job search

Gill: When I came back to California and was job hunting, again I experienced incredible discrimination. By then I had a concept for disability discrimination, not just prejudice but discrimination, and I knew that there were laws out there that were forming to give me some recourse. One of the things that I should probably get on tape is that, when I had experienced these shut doors when I looked for my internship, when I had experienced these examples of bigotry, I would go back to my university and report to my academic advisor and my clinical faculty at the university what was happening to me. A couple times I was really complaining to them, "These guys don't give me a chance, some of them." I remember one guy, I think he was the head of the clinical program, patted me on the shoulder and said, "That's a tough break, that's really not fair. Well, maybe you can reapply next year and we'll see what happens." In other words, they felt no obligation to intervene, which is exactly what they should have done, on my behalf, with me. You know, join forces, put some oomph behind my complaints, but they didn't know anything about anti-discrimination law for people with disabilities and there really wasn't much recourse.

By now, when I was looking for my first paying jobs, I had a sense of justice being codified behind me. I really had a sense that I was fighting an unjust world, that it wasn't my deficits. I was pretty confident about my ability as a psychologist; I wanted a clinical job. So I went out there and job hunted and stupidly asked the Department of Rehabilitation for some help and I was told, "Well, maybe you can take a job as a CETA [Comprehensive Employment and Training Act] clerk." It was so incredible. I came to them with a PhD and they were telling me that maybe I could get a minimum wage job as a clerk. It was clear that they didn't have a clue. And I even tried.

Cowan: This was after Didi Hirsch and back in California?

Gill: Yes, yes, married, PhD'd, all of that, and they were telling me about minimum wage jobs for people who had a high school education. The system was completely unprepared or unwilling to work with me on really finding a job. And at that point I knew that the Department of Rehabilitation as it existed then and as it usually exists is completely bogus, is completely worthless.

Cowan: Is that so, do you think, in every state, or was California or Illinois particularly bad?

Gill: I'm not a policy expert, but I know in Illinois and in California at that time in my location, in Los Angeles, it was worthless. I had to fight to get any help through my PhD because they used to have these rules about terminal bachelor's degrees. If you had a bachelor's degree then their obligation to you was over; I wanted to go all the way. I think I was able to push them to give me some assistance but it was horrible.

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Aside on high school protests

[Tape 3, Side A]

Gill: I wanted to just take one little detour back to high school. I keep thinking of things that I think might be interesting or important to other people, and that is in this special high school, after I got my master's degree, a group of us that hung out together, of Spalding grads, decided to go back and visit the old place. We showed up on their doorstep one day in late spring and I think we were on break from our university programs or whatever. We went in and it was really shocking because they stopped us at the door. We were with a group of people and Larry, my current husband, was one of them. They stopped both of us at the door because they had heard about his antiwar activities at the university and said that he would be a bad influence on the kids that were still in classes in the school if they saw him. I guess he had long hair and stuff.

And they stopped me because one of the things I didn't mention is that my senior year in high school I was elected president of the student council. A lot of us were pretty full of ourselves in terms of what our political power would be and we decided that we would—after learning a lot about the civil rights movement on TV and all that—we decided we were going to do a lunchroom boycott because the school administration restricted what we could even bring in our own lunches to school; we couldn't bring soda.

Soda was some kind of big point with them, that crippled kids in a high school that had health problems should be drinking nutritious beverages and soda wasn't one of them, and they absolutely outlawed soda in the school cafeteria. They didn't sell it and they wouldn't let us bring it and if any of us brought it—and a few kids that were new to the school would just innocently bring soda to school—it was confiscated and taken away from them. We said, "This is part of them treating us like kids because we are disabled. We're not going to stand for it any more." We did some research, it was just amazing, and we found out that all other public high schools in the city of Chicago offered soda in their lunchroom as an option, and that ours wouldn't even let us bring it from home.

So we protested; we politely asked the principal to change the rules and she wouldn't, and so we held the boycott. I think it went on for three days. By word of mouth we asked each other to hold the line and not put one penny of investment into the cafeteria. Most of us bought our lunches there every day. I think we had 99½ percent compliance; no kid bought their lunch, they brought it. I think one day we even all brought soda or something like that, no, it was a real protest. It was wonderful because it hit the Board of Education in their pocketbooks. It cost quite a bit of money to provide those lunches for us every day. For three days they had to throw the food out and lose money—it got their attention.

I have to say this was not all my brilliant idea. There were a couple teachers who in an underground way said, "Did you ever think of not buying their lunch?" that kind of thing, and we said, "Yes, let's do it." We were so well organized and I don't think that special school ever

saw anything like that before. Or since. I don't know, I heard rumors that it happened again a few years afterwards when the kids that were there at the time heard the story of what we all did. Isn't that neat? So we did it—I was

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considered the ringleader. The vice-principal called my mother up and said that I was in with the wrong crowd and I was becoming a communist, which is really funny. [laughter] And my mother, who didn't really know anything about socialism or politics, said, "Communist? Carol? That's ridiculous," and just about hung up on her. It was great, she got no support from my mother.

Cowan: There you were years later the soda pop rebel, queen.

Gill: Yes! So we had that experience in school. Because I had done that, I wasn't allowed in the school when I visited and that was really interesting, so we sat in the vestibule of the school and we refused to leave. We sat there and we kept saying, "This is nuts! We just want to see our old school," and we were arguing back and forth. In the meantime classes were letting out and the teachers were going home, and to go home they had to go past us out the door. They saw us and we knew each other, you know, the teachers, and they would say, "Well, Carol Gill, Larry Voss, what's happening?" We ended up having a few chats with our old teachers. Remember that teacher that had a minor disability? He was still there. He came by and he said, "What's up?" and we said, "Oh, they won't let us in." "Well, what are you doing?" "We're going to school." I said I just got my master's degree and he said, "Oh really, got your master's degree. What do you think you're going to do with that?" I said, "I'm going to become a psychologist." He said, "Yeah, right."

I said, "You don't think so?" He said, "No, you're never going to find work, you know, really. Why don't you concentrate on proofreading? People do really make a good living doing that and it's something you can do." That's the encouragement I got from this poor repressed disabled guy who just couldn't believe that we had a right to be out there and doing things. I'll never forget that because Larry and I talked about it many times and we said he was the most discouraging and he was our brother. He was the one we hoped would be encouraging us and saying, "Yes, okay, you've got a degree ahead of me now, go for it girl," but he didn't, for whatever reason.

Cowan: No one invited you into the classroom to speak to students and show them—

Gill: No. But Larry got the last revenge. When he got his master's degree and his teaching credential, there weren't many schools in the Chicago area that were accessible to his wheelchair, and he ended up having to go back to Spalding and teach, so he got in!

Cowan: [laughs] And was that teacher still there?

Gill: Yes! And they became colleagues! [laughter] It's kind of funny. Actually Larry ended up in the elementary school part of Spalding, but still he saw those teachers and he was one of them then, so that was kind of interesting.

Cowan: Amazing story.

Gill: Those were some of the issues I dealt with as I was trying to find jobs. So I'm in California now, married, trying to find a job, I couldn't. I had that typical experience of looking for the job announcements, sending in my resume, my CV, and people telling me over the phone, "Wow, this looks really good. When can you come in for an interview?" I would show up for the

interview and the job would have just been filled

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or suddenly they had other candidates that looked real good. I realized that it was disability discrimination but I couldn't prove it.

Internships and first job at Glendale Adventist Rehabilitation Institute: seeing the rehab system as exploitative; meeting Barbara Waxman

Cowan: So you went back to California without having a job?

Gill: Right. Larry had his credential and his teaching experience and we knew he would get a job pretty easily, which he did. We knew L.A. was primed for special ed teachers so we knew at least he would be working. Then I experienced this enough that I said, "Well, I want to be a clinical psychologist. I have to log two years of experience to get my license and then I'll have more power and freedom to pick my jobs. I've just got to start working somewhere." So I went back to my internship facility where I had done my internship and they took me on for free, unfortunately.

Cowan: Didi Hirsch?

Gill: Yes. Didi Hirsch had several different programs and they all had their own name. I went to work for the Benjamin Rush Crisis Center, which was affiliated with Didi Hirsch. I had done some work for them as an intern, but now I worked for them a lot more hours to log my practice hours. It turned out to be wonderful exposure to crisis counseling and suicide intervention, and later on when I got involved with ethics issues I really did have some expertise in suicide intervention to bring to it because of that, so things worked out. After I did some hours there I just started calling places and looking for other places that would take me on even as a volunteer so I could log my hours, and Gateways was another one. There was always like one individual that I would find in these places who either got disability or was kind of intrigued by it or saw some kind of opening. There was a guy at Gateways who had been in charge of doing the post 504 review of services and practices at his facility to make them compliant because they got government funding. When he got my call he said, "You could be helpful here with your disability," so they hired me. They didn't hire me for money. They let me go in there, and he supervised my hours so that they would count.

Cowan: Do you want to say his name?

Gill: Kenneth Pope. So they got some pretty good free labor and I got to learn about 504 and I got to learn a lot of stuff about that law.

Cowan: Was that amazing to you? Did you say, "I wasn't aware that this much had been made into law?"

Gill: Yes, I was only vaguely aware of it, and I was pleased to learn about the language of the law and what it covered, and I think I immediately realized it didn't cover enough because it just covered facilities with major government funding. It was helpful to me to learn that.

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Cowan: Do you feel like you experienced some personal growth through those two years?

Gill: Yes, definitely, definitely. While I was at Gateways I didn't just do 504 compliance stuff, I also did clinical work and I ended up working in a locked unit, and seeing the oppression of people with psychiatric labels in locked units was quite amazing also. It also built my confidence as a clinician because I thought once you enter one of those locked units and they close the door behind you and say, "Okay, good luck to you," you're facing all kinds of folks who have been oppressed all their lives and have turned to violence. You do end up feeling pretty competent on the other side.

Cowan: Any connection with Westside at this point?

Gill: No. I know, I was such a disconnected one. Then I started to say to myself, "It's time for me to make money doing this work, and I think I'm pretty good at it," so I did some cold calls to rehab hospitals. I said to myself, "Damn it, there must be some places where disability doesn't count completely against you." I called rehab hospitals and asked to talk to their psychology unit heads and started to say, you know, "Here I am, I've got a PhD, I've got some experience, I want a job." Not too much was happening. Finally, I called this one place and the head of their psychology department started chatting with me; I guess he had a little time on his hands. It turns out I guess he was like an ex-hippie and musician and something about someone who's representing a minority group and the very people that he's supposed to be serving as a rehab psychologist, it must have resonated with him. I knew I had him on the ropes, I knew I had his interest and I don't know how I decided this but all of a sudden I thought, "I'm going to give him a zinger and play on his guilt."

I said, "So how many disabled people do you have on the staff there since you are serving disabled people?" He goes, "Oh well, nobody. That's not good, is it? That's not really right, is it?" He said, "Let me call you back," and that was my foot in the door. I got hired as a member of his staff and within two years he was asked to leave and I was asked to be head of rehab psychology, so I kind of made up for lost time there.

Cowan: You did. And this was at—?

Gill: Glendale Adventist Medical Center. I worked in the Glendale Adventist Rehabilitation Institute.

Cowan: So you became the director?

Gill: Yes, yes, where I stayed for two more years. I was so happy with myself that I got promoted to that position in record time, and then once that happened I began to notice other things more. I stopped being so ambitious about my own propulsion through the system, through advancement, and I began to look at what was really happening at that hospital. I don't want to just target that hospital. I began to review the whole rehab system, critically, medical rehab. I began to pay attention to the people who were being served there not just as patients or clients of my services but as my brothers and sisters. I really began to feel that collective sense with them that I had with people in special ed school. I realized that they were getting screwed and that they didn't have control and it occurred to me—and this is before I'd ever read Gary Albrecht's book *The Disability Business* or anything—it occurred to me that this was a system that was operating for

the advancement and well-being of the folks who ran it, nondisabled people mostly who ran it and profited from it by holding people with disabilities in that powerless position.

I developed such a distaste for rehab and its capacity to oppress disabled people and keep them in their place, and to be exploited for profit, that I walked away from it. I said, "I don't want to do this anymore." I remember planning the day I would leave, and as soon as it was a decision made, I couldn't keep it secret. I went in to the administrators and I said, "I'm leaving on this day. I don't want this job any more." They were shocked because they probably thought they had done me a great favor by promoting me to this position, and I had a fabulous salary and staff and a budget. It was every disabled person's dream really, in a sense, except that I thought I was complicit in the oppression of my people.

By this time I had met Harlan Hahn, Paul Longmore and Barbara Waxman who were all very key people in helping me develop my ideas about disability. I met Barbara Waxman at a sexuality conference at Cal State Northridge.

Cowan: This was while you were at Glendale, during this time.

Gill: Yes. You know, that's not true, I was at Glendale, but I met Barbara actually at Westside Center for Independent Living. What happened is, I reconnected with—I started to go to some events they were holding, and one of them was an event where they were talking about disability and sexuality. Since my clients were really grappling with those issues, I used to go to a lot of disability and sexuality things when I saw them. I met Barbara Waxman there, I believe, and June Kailes, who was executive director there. It was a really interesting evening because when Barbara spoke—do you know Barbara?

Cowan: No. I know June.

Gill: Barbara had a personality like nobody else's, very direct, very funny, and she and June were sparring verbally during their presentations and I liked it. I thought, "They're just like old sisters, like some of my best friends from school," and I really liked that; I missed it. Then, in the Q and A, I asked Barbara some questions, and in the course of my asking questions I identified who I was and talked about my work at the rehab setting. I saw Barbara's eyes get big and lock with mine and she said, "You're cool, you're doing some cool things; I want to talk to you more." And just like other friends I've had, like Joyce, the woman who died who was my mentor, she just was very direct and said, "I like you, I want to be your friend, let's do some things." We became very, very good friends, and it lasted a long time until her death last year. And I met June Kailes, of course.

Cowan: Can I ask you something right in here? When you say, "These were issues a lot of my clients were dealing with," do you mean—were you doing private practice or were these the people you were serving at Glendale?

Gill: I mean mostly rehab, but I did start a private practice in here somewhere. I think it was probably a year after I started at Glendale Adventist because I did get my license and then I was able to start my own private practice.

Cowan: What other issues?

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Gill: I worked like a dog—I used to do full-time hospital and then do private practice evenings and weekends.

Cowan: Besides the sexuality issues, what other kinds of issues came up most frequently?

Gill: Oh, definitely exclusion in their own families, because once they acquired disabilities suddenly their roles changed in the family, people didn't expect them to give the way they used to, people didn't rely upon them, people excluded them from family activities and discourse. Also they were excluded sometimes physically; they couldn't get back in those homes with the steps on the hills. Personal assistance issues; the family couldn't afford the kind of help the person needed to be back at home. A lot of them ended up in nursing homes. I couldn't stand it. There was no reason for them to be institutionalized and exiled from their families and I couldn't stand it. That's one of the things I couldn't stand.

I think the lowest point came—I was not only director of rehab psychology but I was also coordinator of the pain program. We had a guy who was in the last stages of cancer that had metastasized through his body. He was a wonderful guy, just a very thoughtful man. I think he was a professional of some kind before his illness, and even though he had been married to his wife for eons, they had a wonderful romantic relationship. I remember being very impressed by that. He got to the point where he couldn't walk and he was using a manual wheelchair, and in therapies he was being taught to push his own wheelchair. Here's a guy who would be dead in three or four months. We all knew it, he knew it, his wife knew it, and they were teaching him how to push his own wheelchair to be independent.

I remember him saying, "Look at your wheelchair. Do you know, that is cool. If I had a wheelchair like that—my wife and I used to always go for walks every day—I would be able to go on a walk with my wife and hold her hand rather than be pushed by her." So he asked for that kind of wheelchair, and the rehab physician and the physical therapist and the nurses said, "No, no, no, he'll lose conditioning. He doesn't need that, he can push his own wheelchair," and it was voted down. The occupational therapist and I were beside ourselves, and we fought and we pleaded and we gave our best arguments, and we were shot down. Finally I thought, "If a disabled person who knows what he needs can't be heard in this place, I don't want to work here anymore; this is too hurtful, this is too crazy."

Cowan: Kind of a defining moment for you.

Acting Director of disability studies at USC: Harlan Hahn and Paul Longmore

Gill: It was a defining moment; it was. It was one of many, actually—they built up. So I had also met Harlan Hahn and Paul Longmore at various meetings and so on. Harlan Hahn was a political science professor at the University of Southern California [USC] and a very outspoken disability rights activist. Paul Longmore was becoming increasingly an activist. He was getting his PhD in history at that time. Harlan Hahn had started this program that he called the "Program in Disability and Society," which was one of the

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first really established disability studies programs at a university in liberal arts and sciences. That was at USC and it was kind of an experiment. The dean of liberal arts and sciences was Paul Bohannon. He was very taken by Harlan's description of disability studies and the social model of disability, as disability being socially constructed rather than just a medical phenomenon contained in the individual. He said, "You know Harlan, go for it." He gave Harlan a certain amount of support.

When I think the program was about a year old he had hired Paul Longmore. They were building this together. Harlan was going to go on sabbatical so he invited me to be his acting director in his stead while he was gone, and so when I jumped off of the ship of rehab, I ended up in academia. I served for a year in that capacity. I kept my association with the university because I also met at that time some very progressive occupational therapy professors who really got disability studies and were great allies to Harlan Hahn and Paul Longmore and myself while I was there. Betty Yerxa, who is a famous pioneer in progressive occupational therapy theory, who defined occupation as not just employment or gainful work but as the way one organizes one's life in a meaningful way. It was very broad and very cool, very compatible with disability studies. She gave me a clinical assistant professorship and said, "Do with it whatever you want; this will maintain your university status." That was nice, that was a really nice thing. So I did that and then I went just about full-time into private practice from there.

Cowan: Who were some of the other big influences besides Betty?

Gill: There at the university?

Cowan: Yes.

Gill: Well, certainly Harlan and Paul. Barbara Waxman tremendously, because of all of her analyses of gender, disability, and policy issues. I don't consider myself a policy expert at all, but she really was a gifted policy analyst. She could cut right to the heart of an issue, the dynamics of why laws were failing to be applied or what public practices continued to oppress disabled people in their development. She was great at that. It was really fun to talk with her about those things.

Cowan: Was she at USC too?

Gill: No. She was working at Family Planning, I mean, she was a real pioneer. We had a lot in common; she went and created her own job too. She called up Family Planning and said, "What are you doing for disabled people?" and they were sort of like, "What?" and she said, "Well, you need to." She marched in there, she developed her own program, she talked herself into getting hired, and she developed a program to make Family Planning services in sexual education accessible to people with all kinds of disabilities. She was a real pioneer.

Strategies in therapy with clients with disabilities

Cowan: So in terms of your feelings about the culture of disability, what were you thinking now that you were practically in full-time private practice and connecting with the disability community? Can you recall what that was like?

Gill: Oh, yes. At the hospital I was almost like a conduit between all these exciting cutting-edge ideas. My clients were dealing with new disabilities or exacerbations of existing disabilities, and I saw myself very much as the catalyst to shift their paradigm about disability; it was one of my clinical techniques. I would get them to question why it is they were at fault or why they were the ones who were the failure or at a deficit status, and just kind of get them to explore what disability meant to them, to their families, what they had been taught about it before the disability and how that was affecting their ways of moving forward now. That was a big part of the work that I did with people there.

Cowan: Pretty successful with them?

Gill: A lot of times incredibly successful.

Cowan: Rewarding.

Gill: Oh, it's very liberating, and I can tell you this from my personal perspective. It's very liberating to have somebody verify for you what you kind of already know in your marrow, that it should be okay to be disabled, it should be okay to function differently, that the world should not only accept it but welcome it, embrace it, learn from it, be enriched by it, and you just need someone to say, "Yes, you're right." I had a client who came to me and said, "You know, sometimes I think people are prejudiced against me because of my disability," and I said, "Yes, a lot of them probably are." He did a double take and he said, "You're agreeing with me?" I said, "Yes, you're right, I am agreeing with you." I said, "It's a terrible thing, it's a shame, but it's the truth for a lot of us." And he said, "You are not only the first therapist who has ever validated that feeling of mine, but probably the first person."

[Tape 3, Side B]

Gill: It wasn't just this one individual, but he represented a lot of individuals that I talked with and worked with who, even in the bosom of their own family, found no validation for their experience in the world as disabled people. It occurred to me pretty early on when I encountered these stories that that's one of the ways being a disabled person was different from being an African American person or a woman or—not a gay person. I think it was similar to being a gay person because people of color, people of marginal ethnic backgrounds, could at least tell these stories in their family and get a nod from their family saying, "Yes, that happened to me too," or "Yes, those bastards out there are really terrible. We really have got to fight this stuff," or "Sometimes it gets you down," but we weren't getting that validation because our families hadn't experienced it. They couldn't believe, because they loved us, that not everybody else did. They couldn't believe that somebody could actually feel contempt or fear toward us because of our disabilities or that systems were built to disadvantage us, that there were economic

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incentives, et cetera. So they didn't get it and we didn't get validated, let alone get strategies from our families about how to navigate the system. That's what I think we miss as disabled people and very frequently gay people also miss that, that other ethnic communities can give.

Cowan: Good point.

Gill: Yes. So I helped, hopefully a little bit, when I heard these stories to validate them and then once we got past that and people were shocked that I was willing to say maybe they were right, then we worked on strategies. It was really different therapy than a lot of other rehab counselors were doing because they were still stuck on trying to get people to grieve their losses of functioning, and to deal with that and grapple with that, and make bargains with their anger and all that baloney that I never really bought. We were moving on; we were moving on to, "So how do you deal with the bastards out there?" We were dealing with that. Now I feel very vindicated because recently I picked up a book that critically reviewed rehab psychology research from the last two decades or three decades and there was a section in there that reviewed the research bearing on those stages of disability acceptance. It came to the same conclusion that I guess I had come up with experientially, but it said that none of that research has ever borne out that

there are stages at all and that people go through them, at least not consistently.

Cowan: What was an example of one of your strategies that you would offer to clients? What would you suggest they do?

Gill: I wouldn't suggest so much as I would get them to look at their own resources, strengths, you know, opportunities, and problem solve. One of things I did a lot is I encouraged them to talk to other disabled people and to rely on them for support and strategies. A typical thing is when I was in private practice I had referred to me a very active woman who had just learned that she had ALS, Lou Gehrig's Disease, and knew that she would be losing functioning at a pretty steady rate. She came to me to first deal with that reality but then to figure out what she would do to plan for her future. I think that the typical therapeutic response of that day would be to help her mourn her losses and to maybe surround herself with some support network, but one of the other things I did was—well, one day she brought to me the dilemma of, "What do I do when I need a ventilator? The doctor is telling me that there is a place in my disease trajectory where I won't be able to breathe on my own."

I got her to review what her thoughts were about that, what her resources were, her options, was she fully educated, and I encouraged her to get educated about her options. Then there was a point at which she just couldn't move forward because clearly she didn't really know what it felt like to use a ventilator. Rather than do what a lot of therapists would do, I think, about getting her to look inside herself and see if she could tolerate or see herself using a ventilator, I said, "Why don't you talk to some ventilator users." So I helped her, I facilitated her connecting with long-term ventilator users of various kinds, and we used part of our therapy hours just for her to meet with these people and talk with them. I would listen to her conversations and if I saw she was not addressing some issues that I knew she had, I would encourage her to do so. She got a whole education in a very meaningful way that helped her make a very informed decision, and so that's the kind of strategies I would use.

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Thoughts on disability and disability culture

Cowan: How about your own situation, were you, as an adult, did you have issues about being a person with a disability, resent them, feeling "Why did this happen to me?" or—

Gill: I never asked why did this happen to me, no. I only asked, "Why don't they want me to be part of their lives?" That's what I asked. "Why am I sitting here lonely when I should be able to be out in the world doing things?" I never asked why. I can't say the same for my family. I think my mother and father are still torn with that question, why did this tragedy befall their daughter and their family. I just think it's such—that is the tragedy of disability, that my family still thinks it's a tragedy. That is the real tragedy. I wish they could just realize that this has been a great life for me and that it should be for anyone with a disability, or at least most people. I'm not one of the folks who says that physical impairments or any limitations don't have their own cost, I do think they do. So does probably being extremely beautiful or... Lots of other things carry a price. One of the things that is most frustrating to me in terms of my impairment—and I'm using these words in the disability studies context that impairment is sort of the biological or the measurable difference in functioning or structure, and disability is the limitations that society imposes on us, so there is kind of that double part thing.

For me, the hardest part of my impairment is that I can't move as quickly as I want, I can't get as much done. They always ask this question in research, "If you could take a magic pill and become nondisabled, would you?" My answer is, "For an hour in the morning when I take my shower, yes." I still remember being a nondisabled kid, very much; my memories tend to go back very, very far, and I think that's because of the stimulation of having these older brothers who were constantly talking to me and so I encoded a lot of my past in words and memories. I still remember the joy of playing on the neighborhood dirt piles and then running into the shower and taking that shower in five minutes, as a little kid. I really would love to do that, not because I miss the joy of it so much, but I miss the time that I lose every time it takes me an hour and a half to two hours to take a shower.

Cowan: People don't talk about the cost very much.

Gill: We are afraid to because society stereotypes us as such tragedies that we don't want to admit anything negative about this experience or they will think, "Oh yes, we were right all along," and they're wrong, they're dead wrong, they don't understand. The other thing they don't understand is the complexity of human emotions. Something can be extremely hard but extremely good at the same time. My life has just been extremely hard and it's been extremely good, you know, not in spite of the hardness, partly because of it. I think that it's really made me experience my life deeply, and I've thought about it a lot as well. I've thought about it and felt it in a way that a lot of people don't experience and feel their life or think about it. A disability activist in a video—I think it was "Tell Them I'm a Mermaid" that was done by Vicki Ann Lewis and Nancy Becker Kennedy—and I think it might be Nancy Becker Kennedy who said "We don't live our lives on automatic pilot," and I don't, and I'm glad.

Cowan: Do you have any final things of finishing up in California before you moved back to Chicago?

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Gill: Well, culture is important to me. One of the things that happened as I was working with clients in those years in California is I really began to develop my ideas about disability culture. I saw a lot of clients from different backgrounds. I worked with gay clients, I worked with people with AIDS, I worked with deaf people, I worked with African Americans, immigrants, Jews, lots of people that didn't fit the cookie cutter WASP image of the prevailing culture, and in the course of hearing their stories I was frequently impressed by the role of community and identity and culture in building their resilience against society's marginalization of them. I found myself frequently just being captivated by that and thinking, "I wish there was a disability version of that," and then looking a little deeper and realizing, well, there was. The bond I felt to so many disabled people from special school on through my mentors, through the independent living movement and the conferences I went to, there was something there. My husband, my disabled boyfriends and best friends—sisters, you know, girlfriends, there really was something there.

I started to write a lot during that period and I started to write for the disability press. If you look at my CV I wrote, probably in the eighties, I don't know how many articles but lots of articles, for the disability press where I worked my ideas, I shaped my ideas and refined them, and threw them out to other people to get feedback. That's where I developed this idea about the disability culture as something that is sort of there, the roots are there, and that if we were smart, we would develop it. I also, as a developmental psychologist, linked that to what I knew about family and what family does for us and doesn't do for us. I am a strong believer that one of the key contributions of the family is to provide a group of people who are like us in some

way, to help us through in the world that's not necessarily like us. I think we need our families of origin to know a lot more about disability so that they can be there more for us and that they could learn from it and be enriched too, but I think we also need a disability family. Maybe there are substitutes for it that are just as good but I don't know them. I know in my life if I hadn't had a disability family, I don't know where I'd be. I'm very grateful to them. So I began to draw those linkages and other disabled people seemed to really respond to that framing.

Cowan: So this was when you began to write. Do you recall the first thing you wrote?

Gill: Other than stuff like in my own diary and for myself, I think that my first gig was the newsletter of the California Association of the Physically Handicapped—the CAPH newsletter called *New World*, I think it was, and I did a regular column in there, a very short one where I addressed some of these issues. Then I got interviewed by *Disability Rag* a few times, by Mary Johnson, and I think I wrote some pieces for the *Rag*. Cindy Jones and Bill Stothers of *Mainstream* invited me to write for them and I did a regular contribution for them. Then when Evan Kemp and Associates started *One Step Ahead*, they invited me to do an actual "advice column", in quotes, and of course if you read that advice column it ranged a lot farther than advice to essentially disability studies, little disability studies lectures in there. That was my major contribution to the disability press, which I'm very happy I did. It's not going to get me tenure but I'm very happy I did it.

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Return to Chicago, 1990, and founding the Chicago Institute of Disability Research

Cowan: Well then, do you feel ready to go back to Chicago?

Gill: We went back to Chicago because of a confluence of factors. Our son just was turning eighteen. This was Larry's little boy that I definitely became the primary mother figure for. He was turning eighteen and we thought it would be good for him, actually, to leave home and go into the dorms of his university and he agreed. I mean, he was ready for that, he wanted to do that. And since he was already leaving the nest we thought, "We're not really tied here." Our parents were getting older and Larry's mother had had a stroke and we thought we could really be helpful at home. We had built our careers, we could get jobs anywhere now, we were pretty confident and we knew Chicago had improved in terms of access. There was a big independent living center here that had done a lot of work; there was an activist community, we knew that from our visits home and our continuing to keep in touch with people.

The major reason, though, is because we never transplanted well to the culture of Los Angeles. We really didn't live in Berkeley or the Bay Area, so I can't say what that would have been like if we had landed there, but L.A. was a place that always felt foreign to us. At least where we lived in L.A.—we were in the San Fernando Valley in Van Nuys, we had a house in Van Nuys—we always felt that there wasn't enough family commitment. It seemed like the other kids that our son played with, their parents would go off to work and they would give the kids some money and say, "Get your own dinner." We would be the ones who would take them in and try to give them the sense of family being there for them; we were just tired of that atmosphere. There was more racism there than I had ever experienced in Chicago, which is not the public view but it's true. When we heard our son repeating racial slurs we went

ballistic—we didn't like that. The views of immigrants, the views of undocumented workers, we couldn't stomach.

Cowan: How about discrimination against people with disabilities, did you experience that more there than here?

Gill: I think less. I think there was more of a culture, "Well, anything goes," and that was good for disability. We could go to a mall parking lot and the first one of us uses our wheelchair to get on the lift and gets off and then the next one does it, and it didn't attract any attention. The first time we took our lift-equipped van to Chicago, a little audience would gather in the parking lot to watch these strange people disembarking from their van; that was a little better there. I think access was better, but we just really didn't feel that it had the Midwest values that we felt at home with. Plus even the climate, I mean, it was wonderful in terms of being able to function all year round outdoors and not have to shovel snow, but we kind of missed autumn and spring and the seasons. We missed the Cubs and we missed our art museums and our hometown. There's a different culture here in many ways, but we just left it too late. We never felt at home anywhere else, so we came back here.

Cowan: What did you do when you got back here?

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Gill: We, of course, were faced with needing to find employment again, and by this point both my husband and I became interested in doing research rather than continuing our service professions. I had been a clinician. If you included my training stints as a clinician, I had been a clinician for like twelve to fifteen years, and Larry had been a teacher for about twelve years when we left L.A. We thought we had pretty much scratched that itch and had contributed what we could and, you know, we are kind of restless spirits, we wanted to move on. More to the point, I noticed in working with clients that the research literature on disability was terrible. They would ask me questions relevant to their lives and I couldn't answer. Questions about self-esteem, questions about what kind of psychosocial experiences kids thrive on when they have disabilities, are role models important, all this stuff. I didn't have answers to and I didn't think the research literature as it existed had good answers.

I thought what was really missing was enough researchers who had a personal disability experience that could inform their research questions and their approaches to research, that we could really get somewhere. We thought, "Huh," light bulb goes off, "Why don't we do that?" So we got a group of people together that we knew mostly. Some of them went even back to our old special school, but others were people that we had met along the way that we worked with or whatever, who either were disabled and professionals or who were family members of people who had disabilities but were very interested in disability issues. We formed a not-for-profit called the Chicago Institute of Disability Research. We focused on educational and social science research on the disability experience, with Larry's education background and my psychology background. People on our board included people like Paul Longmore.

Cowan: How was it funded?

Gill: We started to shop for grants. We got one of those books—I think we went to a grantmakers library and we looked up that book on handicapped research grants. We started looking around and go, "Oh, Spencer Foundation. They do disability research, they do education research, well, let's try them." Beginners luck! We land our first grant, and it's like we became megalomaniac,

you know, we go, "Wow, this is easy, we can do this." We found out we were pretty persuasive grant writers and so Spencer Foundation funded our study, getting adults with disabilities to interview with us about their educational backgrounds and comparing people who had been "mainstreamed," quote unquote, with people who had been in special ed, and it was interesting. We presented at a lot of places. We developed a summary of it and it's funny, even though it was like our first major study, we are just going to get it published now in its entirety. Because we analyzed part of it but we didn't analyze all of it, and now we are doing the whole thing and we're sending it out there.

Cowan: So this was in 1991, and was it here in Chicago?

Gill: Yes. Well, it was where we live out in the western suburbs.

Cowan: Did you have an office?

Gill: Yes, we rented an office. We started to get involved in a lot of disability activities and they just happened, but we followed up on them. For example, we got here and I wanted to know where to go and get a gynecology exam, so I started asking around.

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People said, "Well, there's this new program at Rehab Institute of Chicago called the Health Resource Center for Women with Disabilities." It came out of a partnership between rehab doctors and women with disabilities in the community like Marca Bristo and so on, and they have physicians who come over from Prentice Women's Hospital to do exams with disabled women. I signed up and I went for my first exam, and I got there and I thought, "Well, this is a pretty good idea, but they could improve this a lot," so I wrote them like a six-page letter. I said, "This was my experience, this is what I think could be better, this is what I would recommend." And Kristi Kirschner, the medical director of that program, read that letter and said, "Do you want to be on our board?" So I got on the board for the Health Resource Center for Women with Disabilities and already had been networking with lots of people with disabilities through that, and we started doing some research projects with Kristi Kirschner and other people on staff at Rehab Institute of Chicago.

One day I was at a disability conference in Washington, D.C. I was asked to be a keynote speaker at the—what was it called? Something about setting a new research agenda for women with disabilities. I met Peg Nosek [Margaret Nosek] there and Barbara Waxman, of course, we met there—we didn't meet but we had a connection there again. And Marsha Saxton, Harilyn Rousso, women that I admire, my heroes, and Corbett O'Toole, I think you know her. Who else was there? Sandra Wellman, the physician with a disability was there. We hung out together, we had a fabulous time, and I ended up during the conference having lunch with the people from NIDRR [National Institute on Disability and Rehabilitation Research]. One of the NIDRR project officers was sitting at my table and she was listening to me talk about the kind of work we were doing and what women with disabilities need, and she said, "You should put that in a grant. Send us a grant proposal."

So then I learned about the Field Initiated Research competition; I didn't know anything about that initially. I also talked with some people from Berkeley Planning Associates while I was there. I think Linda Toms-Barker, Ann Cupolo. Ann I think got married a couple times since I met her so I don't—but I know she was Ann Cupolo. She and Linda Toms-Barker were really gracious to me in allowing me to look at some proposals that they had written successfully, and

I learned from that. I did some work for them, contract work for them, in doing interviews with women with disabilities around health issues.

So we were getting these contract things and collaborations. I took the NIDRR staff person's advice and I submitted a Field Initiated Research Grant on looking at how we could train physicians about the health issues of women with disabilities from the perspectives of women with disabilities, from their input. Again, beginner's luck, it got fabulous scores from the reviewers but didn't get funded. It was like agony and ecstasy. We got between ninety-five and one hundred from all the reviewers and didn't get funded, so I was kind of devastated by that. I told all these women in the disability community about it and they protested. They let NIDRR know they didn't think that was very good, and I guess they were told that our project didn't fit the priorities that year. They told NIDRR in concert—they told NIDRR that they thought disabled women's issues were very important and that it needed to be put high up on the agenda. I'll never know how much of an impact that made or if it was an idea whose time had come, but I resubmitted the next year and I got it. I think it was something like

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\$350,000, and that was a major turning point for us that we tapped into federal funding at that point. That was my first really big grant.

Cowan: So you and Larry were cofounders of this.

Gill: Yes.

Cowan: Chicago Institute of Disability Research.

Gill: Yes, he was the education person, the education guru, and I was the social science person.

Cowan: Did you offer services or were you just doing research?

Gill: Just research. It was a total research enterprise but we did, as I said, form these contractual and collaborative relationships with other organizations. I did the physician training one with the health resource center for women with disabilities at RIC, but I was the principal investigator on it.

Empowered by the ADA, reflections on recent court decisions

[Tape 4, Side A]

Cowan: So you're established here at the Chicago Institute of Disability Research and you just got your first federal grant. That ADA [Americans with Disabilities Act] was passed during this time period when you were setting this up, do you have any reflections on the ADA that you would care to talk about?

Gill: I actually wrote one piece for *Disability Rag* about how it affected me as a disabled woman getting health services. I think the title of the piece was "When is a Woman Not a Woman?" because I felt like I was being asked almost to prioritize my identities, you know, was I a disabled person? Then I should be getting services where disabled people get their services. Was I a woman? Well, it would stand to reason I would go where woman get services; however, there would be no way to get on the table because I use a wheelchair. I had just had a really bad experience where, after going to the Health Resource Center for Women with Disabilities

for gynecology, I was thinking, "Well, why shouldn't I go to a woman's clinic and get these services? We should push that envelope."

So I called up a pretty famous women's clinic associated with a different university and I went to see someone there who had been recommended as a really progressive feminist women's doctor. I called up and made the appointment, and before I got off the phone I said, "And by the way, I use a wheelchair, so I will be able to access your exam table, right?" They said, "Oh, no. Be sure to bring somebody who can lift you." I said, "No, I don't have anybody who can lift me. I'm talking about the services you provide, the accommodations you provide." This was my first foray into securing my rights where I had the ADA in the back of my head; it was the first time I could have the ADA

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in the back of my head, and I have to say it emboldened me. I was checking in with my own attitude and I realized I felt more entitled and bolder than I ever had before. I said, "I think that you need to provide this accommodation for me," and they said, "No."

My husband was in the background listening to this because I use a speaker phone a lot, and he got my attention, so I said, "Excuse me, can you hold for a second," and I put them on hold. He said, "Why don't you ask them if you can speak to their ADA compliance officer" and I said, "Good point, good question." So I got back on and I said, "I'm sure that your facility complies with the new Americans with Disabilities Act. May I speak to the person who is in charge of that, your coordinator for ADA compliance?" and they said, "One moment." There's a pause and then I hear this person get back on and say, "Yes, we will be able to assist you on the table. Just come in, we'll be able to assist you."

Well, it really ended up being a terrible experience, because yes, they assisted me all right. When I arrived I was still in the waiting room with all the other women and I hear the receptionist say, "Oh, she's here, the wheelchair, you know, get somebody," and they went and got some hospital administrators to come. They were the only ones willing to lift me because they knew they had an obligation under the law. So here I have these completely unprepared people in their three-piece suits lifting me onto the table to avoid a lawsuit, and at that point they were imagining the law was a lot more powerful than it actually was and that I would sue their brains out. But I got on the table and the great feminist physician comes in and she says to me—I have my feet up in the stirrups in the position—and she says, "You're just such a remarkable person. You are so extraordinary." I said, "Really? Why do you think so?" She says, "Because you are so happy. Look at you, the condition you are in, and you are happy."

I said, "That's not extraordinary," and I launch into my researcher thing. "Actually, research shows—" and I tell her that "You know, it's not extraordinary. The majority of people with disabilities report quality of life ratings as high or higher than—" and I go into the whole spiel. She just sort of chuckles and says, "You really are extraordinary." I wrote about this in *Disability Rag* and a lot of people said they really related to it. The most important part of that story is that not only did I feel emboldened to pursue my rights by the ADA, knowing that my rights had been recognized at that level, but that I actually used it as a tool and got what I was deserving of, so that was great. It felt like flashing the sword or something.

Cowan: Do you have any comment on the definition of disability that's in the ADA?

Gill: Yes. I know that it's been reviewed and criticized and it's been discussed an awful lot by people who know a lot more about policy than I do, and law, but one of the things that I appreciate about it is that the folks who wrote it, who conceived of it, realized that disability was more than

some physical thing inside of us, that it also had to do with the history of labeling that follows us around. It has to do also with the way we are regarded by others, and those three things are included in the definition and the preamble, and I look at that as disability studies-inspired. So that's important and I use it in my research, actually. When I write a research proposal and I have to define what disability is, what I am referring to when I say disabled person, I use that.

Cowan: Do you?

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Gill: Yes, I do. I say, "It's a person who has a limitation in functioning or has a record of that in some way, or is perceived as that whether they are that way or not but is treated that way." That's the social link, that's the social component, the social component of defining what disability is in our culture, and I do rely on it.

Cowan: Do you think that definition is going to get severely modified through the court decisions?

Gill: Well, I think it is. I think that, of course, like everyone else, this is not unique, but in the recent Supreme Court decisions in employment cases the court completely guts those social links to definition. It ignores the social creation of disability as a category, and so because of that it is a great disservice. It's a great injustice to people who are treated a certain way because of the way society views disability.

Cowan: That social link isn't discussed much, is it?

Gill: No. We've taken a real step backward now, too. It's all about function, and not just function, but it has to be a certain quality and quantity of functional limitation for the court to recognize it as a disability. They've taken our understanding of what disability is and how it operates and how it's produced as a category, and they've taken a giant leap backwards into the medical model. They have put us on notice that it's only medical model understandings of disability that are going to wash with the court, and I resent that deeply. As a disabled person I know that's not where it's at; medical stuff is the tip of the iceberg and the iceberg is social.

Cowan: Do you think it's going to just continue in that way, continue backwards?

Gill: I'm kind of conflicted when you ask that question, because I really believe people should address what they know about and what they're good at, and I'm very humble about my grasp of law and policy, and even history. I like to hear from the experts, and I'm not an expert on that. Where I do have some insight is in how people individually and as a societal collective view disability and how it operates for them, and I do think that every time disabled people as a collective begin to gain ground in equal citizenship there's going to be a backlash. I think society is not willing to give up the role we play in being one of the most marginalized, the most inferior, the most socially disabled of all groups. We are the last bastion of society's sense of superiority and competence, comparing themselves to us, and I think that will die very hard, and whether we will prevail, I don't know. We prevail in small ways when we fight that injustice, but whether we'll prevail in application of the law, I don't know. I think it's going to be a long up and down struggle, back and forth, gain, backlash, gain, backlash; I think that's how people operate.

Cowan: Two steps forward, one and a half back.

Gill: Hopefully one and a half back, not two and a half back.

Joining the faculty of the University of Illinois, Chicago, 1996; building the disability studies program

Cowan: Are you finished with your reflections on that?

Gill: Yes. But I can—if you want me to provide some chronological history, what that first federal grant did for us when we got that research grant is it really was a gateway to our being a pretty nicely functioning disability research program or unit, and it led directly to my being recruited for this position at the university; my work got to be known. I was not looking for doing anything but working as my own boss with a bunch of people that I liked in my own research center, and I was getting very happy that it was getting successful and getting off the ground. Then I got a few calls from this university and people on faculty telling me that they were recruiting for a position, for someone to come in and help build the disability studies programs here. I didn't even really know the nature of these programs, but I knew that I really endorsed disability studies.

I had met Irv [Irving Kenneth] Zola when I worked at USC with Harlan Hahn. I had become a member of SDS, Society for Disability Studies, this time not Students for a Democratic Society. I really was a great fan of disability studies and felt that that was the heading for my own work, the category that my own work fell into. When the university told me about this, I was pretty resistant to the idea of leaving what I was doing to go work for a big institution, a bureaucracy, but I was also intrigued. So I did agree to come out and deliver a presentation at a colloquium here, sit in front of the search committee, and get questioned. I was really relaxed because I didn't care about the job; I just wanted to know more about it. So they asked me a bunch of questions, including some questions about whether I endorsed everything they had done so far and I sort of said, "No, not all of it."

Cowan: At the university?

Gill: Yes, in the disability studies program. I was very open about what I thought they were doing right, what I thought they were doing wrong, as much as I knew of it, and what they should do differently.

Cowan: What did you think they were doing wrong?

Gill: My views have really transformed in a lot of ways since then, but I went into this thinking that I didn't really endorse degree programs, that I thought disability studies was something that should be infused pretty broadly in the curriculum at universities. I wasn't a great fan of degree programs. I think my views have become quite modified now by feedback from students who have been through these programs and I see their importance now. This is not the thing to say when you are being recruited for a position in a disability studies degree program, and you say, "No, I don't really believe in them." There were other things too that they thought were pretty good suggestions, and there weren't enough disabled people on faculty or staff here to give some of that perspective, and I think there were good people who realized they needed that perspective, and so they offered me a job.

Larry and I talked about it a lot, and our board of our not-for-profit, and we were very concerned about having, sort of, to toe the line, other people's agenda. But we negotiated a really nice arrangement here where I was allowed to bring our whole center here, so it would continue. It had a little name change. It went from Chicago Institute of Disability Research to Chicago Center for Disability Research simply because, at that time, our department here at the university was called, the Institute on Disability and Human Development, and we didn't need two institutes. So I agreed, I came on board, and I haven't regretted it; it's been a really exciting ride.

Cowan: What would you say the value of disability studies is?

Gill: Its accuracy in really investigating what's important about disability, investigating it with an accurate grasp of what the phenomenon is. It looks at that iceberg under the water, not just the tip, and that's where disability research has been hung up for decades, is just looking at that tip. It allows people with disabilities to inform and help direct research in ways that, as I said, accurately reflects their experience but also yields results that are more useful and relevant to their real life dilemmas. When a disabled kid goes to school and isn't successful, it isn't because he doesn't have full range of motion of his arms; it's because he is confronting an educational system and a society that doesn't see him as part of the group. Looking at it that way again is that paradigm shift. I told you, I think, as a therapist I did a lot of paradigm shifting and in disability studies it had all been done for me already. All the scholars that came before me shifted that paradigm in a way that made sense to us and that really improves disability investigations.

Cowan: Are you getting an infusion in the curriculum that you mentioned, or do students from other majors come into the classes? Does that happen very often?

Gill: I think we are getting both, which is really fun. We are getting both a concentration of young scholars—I can't say young because we have them of all ages—but scholars who are new in their exploration of disability. We are getting a concentration of people who are dedicated to that from the get-go and who want to speak to like-minded people, and that's what the degree program does. It brings scholars together who can talk with each other, who can review each other's work at a very high level. I hadn't thought enough about that, that that's what a degree program could do, and that's important stuff.

Cowan: Good.

Gill: Yes, so there's that, but we also are really building bridges throughout this university. The more that disability studies gets recognized as a legitimate field, the more it's written up in the *Chronicle of Higher Education* and coverage on the NBC nightly news, the more attention and respect it's garnering across the university. The administration backs it and we have all of the departments in liberal arts and sciences, art and education, the health sciences and so on, who are perking up and saying, "What can we learn? What can we offer?" We are having some really good dialogues and collaborations.

Cowan: Is it having an impact in the outside world, for example, in departments of rehab?

Gill: Yes.

Cowan: How have you seen that manifested, if at all?

Gill: Because I'm not in that system on a day-to-day basis, I don't yet know how much it's really affected the end user. I don't know if it's really made services more relevant, progressive, and client controlled; I don't know that yet, although I do see instances of it. Certainly here in Chicago at the Rehab Institute of Chicago, there's a long relationship between Access Living, the Independent Living Center, and Rehab Institute of Chicago, and disability rights has certainly made its mark on services at that institution. I don't know how broad that is across the country or around the world, but I do know that when I read rehab psychology research, I'm still very frustrated with some of the old-school ways of looking at disability that I see there. I really see that the challenge has reached the top, that many articles ten, fifteen years ago that would never have addressed the social model of disability are discussing it, they're calling it that.

Cowan: Instead of the medical model.

Gill: Yes, not just that, but they're even moving beyond sort of what I call the progressive medical model, which is to say, "Well, disability is in the person but the environment has a lot to do with what the person ends up being capable of doing," but is beyond that, to even questioning disability as a socially constructed category, and that's pretty exciting. You know that that will have ramifications. You have disciplines like occupational therapy where I hear there are still a lot of traditional programs that are medical model-based, but a good number of them now are looking at disability as a social construction. Just like in critical gerontology, there's more emphasis on how society excludes people unfairly on the basis of biological difference; there is definitely that happening in some of the progressive health fields. And you have NIH, National Institutes of Health, even considering it an advantage when researchers are now exploring disability narrative, looking at health and disability experiences from the customer's point of view, which is great. That's a cornerstone of disability studies—that the voice of the person who's experiencing it gets privileged. And you do have researchers all the way up to these medical research funding agencies that are supporting the privileging of that voice, and that's pretty exciting and that's pretty new.

Cowan: I was going to begin asking you some questions about your association with Not Dead Yet, but before we do, do you have any final thoughts there on your experience here at the university?

Gill: Well, I just heard myself sounding really positive and for a moment I thought, "How is that going to look on the transcript?" I don't want to seem too sanguine because it's far from positive across the total landscape. Even though I don't work in rehab day to day, I hear the stories from the research informants in our projects when we ask people with disabilities to go into focus groups and tell us about their health service experiences or their educational experiences and so on—I know the horror stories still prevail. I know that people with disabilities are still not having enough control. I know that they're still being categorized and limited by archaic understandings of disability, so I'm not here to say that rehab has seen the light or special education has seen the light or anything like that. But I still believe strongly in the liberatory power of social model thinking, of that disability paradigm shift.

I think it is slowly sinking into a lot of different areas, from the grassroots of the disability rights movement to that disabled person cloistered in their home because they don't have the money or the help, or the technology, to find an accessible place or get out of the place that they're in, but who picks up a magazine that some health professional recommended, like *New*

Mobility or even *Mouth Magazine* ; I see *Mouth Magazine* in rehab waiting rooms, I mean, it's amazing, and that's pretty radical. They see that and they read about their laws and they read about a protest or demonstration. They read the story of someone who's had a similar experience, and so it's reaching them—it's reaching people who are not connected and they're getting connected.

The thing about disability culture is amazing. When a number of us started talking about it in the early eighties, it seemed like a foreign concept. Now I can't tell you how many times I'll be surfing the Net and seeing people's individual home pages, or I'll read a research study that asks people with disabilities for their views on something or whatever, just a broad spectrum of materials and sources. And I see that word "disability culture" all the time, like it's a household word; that's amazing.

Cowan: I imagine that the Internet has been quite a facilitator of that concept.

Gill: Of community, the virtual community. Yes, absolutely. It's really fun. It seemed once in the early eighties that if there was something like—if there was a person who was a disabled artist or film maker, we almost all knew who they were because there were so few people who had the advantages to get that far to do those things. But now I surf the Internet and I see fabulous beautiful paintings and artwork and articles, writings, essays, by people with disabilities whose names I don't know and I think that's just wondrous. It's wonderful that there are people there who are not any longer a small insular group but they're all over the place doing the culture, and that's really exciting and gratifying to me.

Not Dead Yet and the Elizabeth Bouvia case, 1986

Cowan: I was going to ask you a few questions about your affiliation with Not Dead Yet. Do you want to comment on the organization or on your ethics work with it or—how are you associated with it?

Gill: Let me tell you that this is probably where I'm going to make a lot of enemies, but I think the right-to-die debate in the disability community is the most important issue facing disabled people today.

Cowan: The most important?

Gill: Yes I do, it's life and death.

Cowan: Why is that?

Gill: Because I think that people with disabilities are dying unjustly daily. They're dying because either they or their medical professionals or their family, or all of them, are not

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able to articulate what their real problems are. Their different bodies, their different minds, are being scapegoated for their problems.

Cowan: Would you explain what you mean by what their real problems are?

Gill: The individual who got me into all of this is Elizabeth Bouvia, the woman who was twenty-six years old at the time in the early eighties, who was the first and most prominent disabled person that I know who was in the news because she said that she wanted to die; as a disabled person she couldn't take it anymore, whatever it was. She checked herself into Riverside General

Hospital in California while I was in California, so I heard a lot about her in the headlines, and she said she wanted to die because she was a person with a disability. I have to tell you that at first I sort of noted this phenomenon and said, "Gee, that's sad, that's too bad. That's too bad she feels she has to do that, but she's a grown woman, I support her self-determination, and she has a right to make that decision." Boy, was I dumb, that's exactly how I saw it and I'll admit it.

Then I got a call from Barbara Waxman, then I got a call from Paul Longmore, then I talked with Harlan Hahn and a number of other people in the disability community who said, "You're a psychologist, you have a disability, you've got to do something, you have got to get involved in this." I said, "Me? I'm going to tell this woman who knows a lot more about her life than I do what to do?" They said, "Yes," and they said, "You know why? Because it's a political issue," and they laid it out for me.

[Tape 4, Side B]

Gill: They said that they had done a little investigating into the facts of her life and they said, "Would this change your mind? We discovered that she grew up in an institution where her family placed her. As soon as she could, when she was eighteen years old, she checked herself out and has tried to live independently since then. She has had one obstacle thrown in her path after another. The Department of Rehab said that they would give her a van as long as she was in school, and I'm thinking already in my head, "Oh yeah, Department of Rehab, I know how they work. Okay, tell me more." So they said, "She had this van, she got a degree, she went on to get a master's degree in social work." Okay, now I'm even identifying more, right? This isn't so different from my life. So they said, "She's working on her master's degree and it comes time for her to do her clinical placement, field placement, and she says where she wants to work. They say, 'No, no, you have to work with disabled people; you're disabled, you know, you need to work with disabled people.' She said, 'No, I want full choice.' They said, 'No, we're sorry.' So she's discriminated against, she quits the program and when she quits the program, the Department of Rehab takes her transportation away, so she gets the rug pulled out from under her.

She has two suicide attempts when this occurs, and she used drugs and alcohol to do them, and I guess at one point put herself in the path of traffic, or whatever. But she got through those periods and starts corresponding with a prisoner. He gets out, they get married, they're living in poverty. He's having trouble finding work, she's having trouble finding work. They start cheating the welfare system so that they could continue her benefits and not report her marriage, but they are afraid they are going to be found out. She gets pregnant, she's thrilled, she has a miscarriage. Her brother dies,

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her mother gets diagnosed with cancer, her husband leaves her, and then she checks into Riverside General Hospital, twenty-six years old and says, "I don't want to live anymore. Please give me morphine while I starve to death." The ACLU hears her story, comes to her support and says, "Yes, this poor woman, life is untenable with her disability. We support her right to die."

Well, when I heard the facts, I saw that it was just another common but terrible story of a person who tried to live, tried to live according to her own self-determination, and was beaten down at every turn. And it sounded like what I used to tell my friends and my clients that I called "disability burnout." It wasn't burnout from living with our different bodies or our different minds; it was burnout from the system's and societal treatment that we sustained, that we were

exposed to on a daily basis. They said, "Hey, you know, Gill, disability burnout, remember?" and I said, "Yes, you're right."

So I joined them—we even formed an organization around this issue initially, and we filed an amicus brief with the court, and we got involved. The details are not all that important. We were present in the court that heard her case and initially turned down her appeal and said, "She should be treated like anybody else who doesn't want to live and certainly not be helped to die," which we thought was a great decision but it was overturned. She won her right to die, but it took so long by then that she ended up living, and she's living independently with assistance to this day somewhere, as far as we know.

Cowan: So you would say her real problem was lack of support.

Gill: I think I would say it's stronger than that.

Cowan: What would you say?

Gill: Her real problem was a society that thwarted every effort of hers to live the life she wanted to, but the moment she said, "All right, I give up, I want to die," they said, "Oh, let us help you." That is the heart of discrimination, right there; that's what it's all about.

Cowan: Because if a healthy person—not a healthy person, but if anybody came into a hospital and said, "I want to die," they wouldn't say, "Let me help you."

Gill: Certainly not. Actually, this hospital was almost exemplary. They got a psych consult, and I think they ended up moving her to the psych ward, and when she continued to refuse to eat they did a nasal gastric tube and they fed her, to keep her alive. She was losing weight. They were afraid for her. They tried talk therapy, it didn't work, so they did that. They saw her in a very complex way as somebody who was trying to exert control in a way that was self-destructive because there weren't very many other options for control of her life that she was offered and allowed, and I think they had that right. But, yes, she was helped to die. The lead attorney who finally won her her right to die ended up blowing out his brains with a gun a few years after that. He was the cofounder of the Hemlock Society. She had all the Hemlock people behind her.

She was the first of many cases. Then we had the nursing home cases, David Rivlin in Michigan and Larry McAfee in Georgia, both of whom were in hospital settings,

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institutions or nursing homes; David Rivlin was in a nursing home. Not Dead Yet calls these cases, "Give Me Liberty or Give Me Death." They were both men who wanted to lead their lives on their own terms and instead, because of financial insufficiencies and lack of adequate funding and lack of adequate personal assistance services, they were institutionalized; they were in prison and they couldn't stand it. Like many prisoners, they would rather die than be in prison. That's how the disability community framed the issues, and of course the press and a lot of the health professionals and the public framed it as, "Disabled man no longer wants to live imprisoned in disabled body." We knew how wrong that was.

But there have been other cases, Kenneth Bergstedt. And now the precedent for refusing, quote unquote, "treatment," has been expanded to taking away food, water, and ventilation; air, food, water—those are considered treatments. When a person with a disability gets adequate assistance to eat either by feeding directly from a spoon or tube feeding, it's now referred to in all the court cases as artificial nutrition. If I eat my own turkey as I did at lunch in front of you,

if I can put that fork to my mouth, I'm eating naturally, but if my hand gets tired, which it often does, and I ask my husband if he could scoop up the last few bites and give them to me, that's artificial nutrition. That's ridiculous, because it's part of our disability lifestyle to get assistance to do things; that's part of what we do.

Issues of assisted suicide and prenatal screening for disabilities

Cowan: In the case of the state of Oregon where they have passed an assisted suicide law and it affects—it has kind of a defined thing, but it isn't if you have a disability, it's if you have a terminal illness. How does your feeling relate to that situation?

Gill: I have to tell you I wear two hats on this issue, one is as a disabled person who also has, arguably, illnesses, and the line between terminal illness and disability can be pretty fine. I'll tell you it is, because in '89, I began to have pretty severe respiratory problems, and we don't need to go into the details but, long story short, I was told that I would die if I didn't start using nighttime ventilation. So every night I use a positive pressure ventilator with a nasal mask that fits over my nose and helps push air into my lungs. I say I use a ventilator, no big deal, but the media and many doctors would say, I'm "on a ventilator" at night, as if it's tragic; I'm a passive recipient of technology that I'm hooked to artificially, I'm artificially breathing. I don't see it that way at all. I mean, there are nights I can't wait to get into bed, put that thing on and just relax; it's so relaxing and refreshing and I'm just lulled to sleep by the hum of it. I love it. It's my friend. That's not how it's portrayed in the media. It's portrayed as this horrible dehumanizing invasive technology people are hooked to when they are at the end of life and it's tragic. Yet if I didn't use that I would be dead pretty soon. Am I terminally ill? I am under the Oregon law, so I get more of a right to those pills, you know.

And then the other part about these assisted suicide statutes is that sometimes they reference the fact that people who request assisted suicide should be informed of their options. I don't know one of them that says that they should be able to get those

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options. Nobody guarantees that they'll have those options, and that's the rub. David Rivlin, in that nursing home, was given no options.

Cowan: He could have been told about them but would not have been able to receive them.

Gill: He could have been told, "Well, you know, you should get personal assistance services and live in your own home," and he could have replied, "And how do I do that?" They would have said, "Well, sorry, in your circumstances, we can't really give you the hours you need," which is exactly what he was told. The government was willing to spend a lot more money keeping him in that nursing home than he ever would have needed to live in his own home. So, as a disabled person, I look at it with that hat. As a psychologist, I look at it purely from the perspective of suicide, and I know a little bit about what goes through the mind of somebody when they say, "I want to die," and I know about the hidden ambivalence in that wish. I know about the interest in what other people's reactions will be when that wish is stated, and I know how vulnerable people are when they are in that state to any suggestion by others that maybe it would be good if they did die. And yet that is the situation disabled people are in all the time, and even terminally ill people, and I am concerned about them too.

I've worked with dying people in hospitals, and I know that it's one of those things; death can be very hard, but once again, are hard things necessarily bad things? We've heard from lots of

people who have feared dying and who have thought about ending it early, people with AIDS, people with cancer, who say at the end that they were so grateful that they had the support to live to the end, because that was when some of the important moments happened for them. I'm not suggesting that we force people to live so they can capture those Kodak moments, but I am saying for me as a therapist, a health professional, which I was a licensed health professional in psychology, for me to treat one class of people differently than another, for me to exempt them from my professional standards when I hear somebody tell me they want to die is discriminatory and should be illegal, and it is illegal in most places.

That's the thing, there's good reason why the health professions and the mental health professions are supposed to respond to statements of suicide or requests for assistance to die the way we are, because there is no way to take that back when the person dies. Family members and health professionals carry extraordinary weight in their responses to individuals who are vulnerable and on the brink of giving up. Our message should always be—first of all, it shouldn't be a message. As I've written and I've said many times in presentations, there is only one appropriate response from a health professional of any kind when a disabled or terminally ill person says, "Doctor, I want to die," and that is to ask why. We owe it to those individuals; we owe it to every standard of ethics and morality in a civilized culture to question that, to not support it reflexively. To question it and see what is that person really missing, what is really the problem that they want to die, rather than go through the human process of preparing for death or living with a disability.

Cowan: So is there ever an answer that would be an answer that would allow them to choose?

Gill: I can conceive and I actually have answers that might make me as an individual think, "Yes, that person really has looked at all the alternatives, knows themselves really well, they really are in desperate circumstances. Maybe it's a good decision for them to take

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their life early." But I do not think that we build laws around that because we live in a society where once that gets codified—first of all, it's open to practitioner error in judgment, I mean, I may think it's an adequate time. But then, let me give you an example, which may not be really popular. I've worked, as I said, with lots of clients from different backgrounds and I've had people come to me and say, "I'm gay, I hate it, it's not what I want to be. I'm dark skinned, I hate it, I can't stand it, it diminishes my quality of life. I'm not like that inside, that's not how I feel," and have talked about destroying themselves.

Now, what if I am some kind of, I don't know what, someone whose value system resonates with that belief and I say, "Yes, that makes sense to me, I understand." Why would I think because a person has a physical difference or has an illness that that makes so much sense that I should then as a psychologist or a doctor help that person and say, "Oh yes, that's rational, yes," but I wouldn't say that for the gay person who couldn't stand being gay or the woman who couldn't stand being a woman, or a person with dark skin who couldn't stand it, it doesn't fit with how they see themselves? Why do I feel it would not be my place to actually assist and make sure that person is dead in those cases, but it's okay for people with illnesses and disabilities, especially when I know it isn't usually anything innately physical or biological that is the problem of disability; it's the way we are treated.

Sure enough, there hasn't been much research until now, but now we are beginning to see research studies that address that "why" question. Why are people with terminal illnesses asking to die in Oregon and why are they getting those lethal prescriptions? What we are

finding is it's not pain like the campaigners said; it's not almost anything that has to do with the disease process; it's not fear of death. It's fear of being a burden on others; it's fear of needing help to go to the bathroom, to dress; it's fear of being rejected because you are no longer aesthetically pleasing; it's fear of not being in control anymore, because if you're not physically in control, people assume you can't be in control. These are socially mediated reasons. People shouldn't have to die one minute early because of a problem that's socially caused and can be socially fixed, and that's why I don't approve of the Oregon law.

Cowan: That's a really thought-out explanation.

Gill: Well, thanks, it better be after all these years of writing about it. If you're interested in *Not Dead Yet*—

Cowan: But wait, I have one more question, and that is the aborting of fetuses who will have disabilities when they are born, what are your thoughts on that?

Gill: Again, as a disability studies scholar, I always look at disability as a social category and I can't help then drawing analogies to other socially constructed categories like gender, sexual orientation, and race. I think it's absolutely true that there are a lot of parallels. I don't think it's exact parallels. I'm not saying that having a disability is like being a person of color; I'm not saying it's like being a person who's gay, and yet the discourse around things like gayness and the search for a gay gene that some scientists have talked about has some similar elements. There's a lot of misunderstanding about the potential of life quality for people with disabilities, and one of the things that concerns me—I don't have all the answers about this dilemma, if I haven't said that already—but I do

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know that I can identify some of the problems that keep society from practicing or responding to these dilemmas in a just way.

One of them is that fetuses with disabilities are rejected because they will become human beings with disabilities, and human beings with disabilities are devalued. A lot of times we hear the argument that it's kind to abort a disabled life in the making because of the potential quality of that life, and I think that most of those arguments are specious. In fact, most of the time, that decision is made not on what that person's quality of life will be but what it's perceived to be. As long as that's the case, as long as parents are getting neither adequate information nor adequate support for all the options including raising a disabled child, then I am going to have problems with the practice. These are two examples of terribly thorny human dilemmas, that if we lived in an ideal world where disability was absolutely not only accepted but embraced and appreciated, I might have completely different views about assisted suicide and about prenatal screening, but we're not there. We are very morally and politically immature on the issue of disability, and it's premature to be able to end the potential of continued life with disability on the basis of our understanding of disability right now.

Now, like a lot of disabled feminists, I tell you that my position on prenatal screening is a little bit more nuanced than it is on right-to-die issues, the only reason being because on assisted suicide the cost of mistakes is a developed human life, is a loss of a person. With prenatal screening, I don't recognize a fetus as the same as a living person. I told you my background is Catholic. I'm not a practicing Catholic; I fell away from the faith very critically. I don't subscribe to organized religion. I have a great soft spot in my heart for people that do, because that was my background. I love many of the progressive passionate Catholics and people of

other religions that I meet, good people; I like moral people, no matter what the source is. But for me, I'm able to tolerate more possibility for error when we're talking about a fetus than when we're talking about a life on this earth. I think that that's really different for me. And I do feel very differently about an individual woman's right to have a pregnancy or to terminate it than I do about setting into law, standards that predicate the right to terminate a pregnancy on the basis of disability. When it begins to be codified as disability being an okay reason to end a pregnancy, I get very squeamish because it's based on judgments about the value of that life after it's born.

Relationship with Not Dead Yet, advocacy and academia

Cowan: But your association with the movement, the Not Dead Yet movement, are you affiliated with them?

Gill: I consider myself a consultant for Not Dead Yet, and their founder is someone that I very much respect. I met Diane Yester [now Coleman] during the Elizabeth Bouvia court proceedings. As one part of the disability community's response to the Elizabeth Bouvia case, a bunch of us actually formed a picket line and picketed in front of the building of the southern California ACLU because we were so pissed off with them about not seeing this as a political issue and only interpreting it through medical-model understandings. We did our best first to educate them, to appeal to rationality,

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emotionality, whatever; we tried to dissuade them from their position, and they continued to help her die legally, so we picketed them and sang, "We Shall Overcome." Some of them came to the windows and cried because they couldn't believe, these good progressive liberals, that any group would be protesting them and singing, "We Shall Overcome" against them; some of them were quite shaken up.

In the picket line was a petite young woman using a power wheelchair, dressed in a business suit. I didn't know who she was, and someone later said, "Oh, that's Diane Yester," and that was her married name. "She's an attorney for the state of California." I thought, "Oh, that's interesting." Then later on I ran into her in meetings we were having with the ACLU in which we were arguing with them, and she was trying to help with her legal background and so on. Then I continued to see her at various disability meetings in California and she just became Diane Coleman, and I got to know her and we actually became friends; I think that we really respect each other a lot. She spent a lot of hours talking with me about Elizabeth Bouvia and about the greater issues of disability and the right to die. She became increasingly concerned, and I don't even know exactly when Not Dead Yet was founded, but I think it was the mid-nineties. She called me one day and said, "I'm going to do this." I said, "Great, but I'm not going to join it, and the reason I won't join it is because I still feel I have a lot of work to do as a researcher, and I have to keep my mind open on this issue."

I think I can really do that and I think I can stay pretty engaged with asking the questions and looking at the answers, and I don't want to muddy that with political advocacy on the issue. Right now I want to be a researcher because I think there are a number of political advocates who are trying to protect our lives by working through Not Dead Yet. There are a lot of disability rights organizations who have joined them in their position. What we don't have are a lot of researchers who will frame these questions from a disability perspective, and that's the contribution I want to make.

Cowan: Has the ACLU changed their position on this?

Gill: I don't know that southern California has. I've heard rumors that chapters across the country have come up on different sides of these issues, but I think, in general, those who consider themselves political progressives and particularly libertarians view this as an issue of personal autonomy. We have our libertarians within the disability community; there aren't that many, but there are a few, like Andrew Batavia and Hugh Gallager. They formed an organization called Autonomy in opposition to Not Dead Yet, and I understand that Lauro Halstead and David Gray have joined them also.

[Tape 5, Side A]

Cowan: Carol, I just have some general questions for you, one of them is on your writing. I believe you mentioned a conflict between advocates, disability advocates, and academia. Do you want to comment on that at all?

Gill: I don't think there's a conflict, but I think that a lot of people question whether they're compatible. I think in disability studies most of us who are disability studies scholars feel that they're extremely compatible, not only compatible but necessary; it's a necessary alliance. I always talk about two of my guiding values in scholarship and research, and they are rigor and relevance, and I can't prioritize one over the other. I

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think they are both absolutely necessary and they complement each other. I think part of what has been wrong with some disability research from the past is that the researchers have prided themselves on being incredibly rigorous. They carefully, randomly sample individuals so that they don't exert investigator bias over who gets chosen to be in this group versus that, the experimental group versus the control group. Or they construct personality measures or whatever disability-related measures, attitude measures, and they use the best statistical techniques and tests to judge whether they are valid and reliable and so on. Okay, I applaud them, they're rigorous. Now, whether what they are studying has anything to do with the real disability experience of people as they report it or whether what they're studying is of any interest or importance or use to people who live with disabilities, that's another matter, and in fact that's where there's been a lot of slippage.

The investigator, who usually doesn't have a personal disability experience, who frequently doesn't see disability as a complex multiply determined phenomenon that's as much social as it is physical, that individual decides what the research question is, how to approach it, and what the right answer should be, and that's where it's gone wayward. I think what we need is very carefully done, in other words rigorous, research, but research that remains guided by the disability experience from the perspective of people with disabilities. I think that we should be spending more of our research dollars researching issues that disabled people think are critically important to them, and that's what we try to do in our center. We have a lot of dialogue with people in the disability community. Sometimes they bring issues to us and we just take their lead and say, "Okay, let's build a study around that. Let's get some funding, let's do a demonstration or an education project around it," and that's what we do. So I think rigor and relevance are really important.

One of the reasons why I wanted to clarify my relationship with Not Dead Yet is I've heard my own work or the work of fellow disability rights advocates being impugned by others as biased because we have positions on disability issues, we have concerns about political issues or

disability rights, we have political sensibilities. As if those who consider themselves objective rigorous researchers are not themselves dealing with their own biases all the time, whether they are aware of them or not, as if there is such a thing as purely objective research attitudes going into a project. It's just that so much of what traditional researchers, so much of their bias has remained unaddressed and unidentified because it happens to be congruent with prevailing societal viewpoints.

It's the same thing women went through in women's studies. Men didn't recognize in their research their biases against women on many levels in their research, because the prevailing norms were male and they were men, so where's the problem? We have a very similar thing happening in disability research. That is not to say, and I want to go on record as saying, that I'm not saying that only disabled people should be researchers, for a lot of reasons. But I do think that in some areas there is an epistemological edge to having some direct experience of disability, and there certainly is a lot of reasons why people with disability should have much more access to research positions, research leadership, and research control than they do. But no, I'm not saying that only disabled people can do research. I think that much more of it, though, should be enlightened by and even directed by the disability perspective than it is now. I'm concerned about people who have looked at my work and the work of other people and said, "We discredit that," because they are political ideas.

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Disabled women's issues

Cowan: Well, bringing up that gender issue that you just did with women's studies, do women with disabilities have particular problems that men with disabilities don't? Is there still a gender issue there?

Gill: Yes, absolutely. I think in a lot of areas of life and a lot of women with disabilities are getting pretty tired of that model for understanding our experiences that says, "We bear a double stigma or a double disadvantage. We're a doubly disadvantaged minority group because we're women and we have disabilities." That's kind of an old tired thing for a lot of reasons, including the fact that we are not just a double minority, many of us have multiple minority statuses if we're lesbians, if we're women of color, and those minority dimensions that are also socially constructed really affect our experience and our status in society as well. The other reason that the double disadvantage model kind of breaks down is because women with disabilities, like a lot of other minority communities, don't want to just be defined in terms of disadvantage. We also have an affirmative view of what being a disabled woman brings to our lives, and you certainly see that if you surf the Net. Again, and if you just put into the words "disabled woman" or "women with disabilities" into a database, you'll find all of these incredibly lively dynamic web sites by women with disabilities who are celebrating who they are, who are proclaiming to the world who they are. And although they certainly deal with their social obstacles and disadvantages, that's not the defining factor, that's not the critical factor in a lot of their experience.

It reminds me, you know, I'm very interested in disability identity and a lot of my research is in that area, and I've read a bit about other minority identity models. There was a model of black identity developed in the seventies by a researcher, a psychologist, named William Cross. Initially he talked about how African Americans develop a sense of black identity to

insulate them against the stigma and the disadvantages that are visited upon people of color, but over the years he's also now introduced the affirmative part of that, which is a celebration of black culture and ancestry and history and so on, as in itself motivating people to develop a black identity. I think that disabled women are, in a sense, following that same sort of pattern, that we certainly are outspoken about the disadvantages that we experience as members of society, a society that doesn't embrace our gender or our disability status or anything else that's marginalized, but that we also are coming together in community and celebrating who we are.

Cowan: I have a question on health access and people with disabilities. Is that going to be a problem that's solved without health care access being solved for everybody?

Gill: No, no, I personally don't think so. Again, a lot of times when I look at the status of people with disabilities, it's like the status of other disenfranchised groups, sometimes only more so, more concentrated. Some of the health inequities that are horrible for everyone, especially for economically disadvantaged people, can be critical life and death disadvantages for us, they're just a little bit more concentrated. I think that women with disabilities have done a tremendous amount of political organizing and mobilizing around health service inequities. There's a lot of research, a lot of it being done by women with disabilities asking other women with disabilities to tell their stories about health access, health service access; that's been really important, I think.

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We have organizations like the Health Resource Center for Women with Disabilities at Rehab Institute of Chicago, which has developed a collaboration, a partnership between disabled women health activists in the community and the health professionals at the hospitals who work with them in getting a broad range of services to be accessible for women with disabilities. These are good things that I think have been fruitful outcomes of the health activism of disabled women, going all the way back to some of the work that Marsha Saxton did with the Boston Women's Health Book Collective, and other health activism.

Cowan: Do you think there's a hope of universal health care provided on the part of the government, or do you think that's just a pipe dream?

Gill: Not in the current administration. I don't know, maybe my boomer generation will be able to push for that. Maybe the critical mass of us and—you know, I try to balance between my idealism and my realism like all disabled people do, and I would like to think that AARP [American Association of Retired Persons] is going to embrace disability issues and that we're all going to redefine what disability means. And we're going to see it in much more user-friendly terms, and we're going to push for our entitlements together, and that someday people won't fear disability as the end of the world as they do now. I like to think that we have enough numbers that if we can turn that trick in our minds we will be able to do that, but I'm just not sure it's going to happen. In the meantime, I don't think we can wait for it. I think that groups of us have to form collectives of activism around this, have to try to put resources in place the best we can.

I don't know, by the time anyone listens to this tape or reads my words years from now, they'll know whether it happened or not, but a group of us with disabilities are thinking of developing some kind of collective arrangement where it would be an alternative to nursing homes but still be somewhat communal and collective, so we could rely on each other to administer the kind of services we are going to need increasingly as we age, including some kind of cooperative

living situations, but that we would like to make it a model where we stay in control to the final breath. That's going to be a real challenge, but if we can pull that off, it will benefit everybody in this country tremendously.

Raising a child as disabled parents

Cowan: Everybody. It will. Well, Carol, is there any kind of final summing up you want to do?

Gill: One of the things we didn't talk about very much was child rearing and developing our own families. I don't know if I need to say a lot about that because I know that we have Through the Looking Glass now and we have parents with disabilities coming forward with their stories and their strategies, but I can tell you it was a lonely experience raising a child of the majority culture when both my husband and I had disabilities. Sometimes we found it very complicated, and it feels almost like it must feel in families where people are from different cultural backgrounds. I've written about this a little bit, when white families are raising children of color and transracial adoptions or when there's

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marriages between people of different racial/ethnic backgrounds that seem very different to the world. I think that we experience some of that.

Sometimes our child viewed us, his parents, in a way that was completely in conflict with how outsiders viewed his parents. I remember instances that had to be extremely hard on him—I know they were on me—like when he was wearing contacts for the first time when he was twelve or thirteen and he hurt his eye; he had a corneal abrasion. We went into the emergency medical setting to get that taken care of and I went in there with him. The emergency room folks, even though I spoke first and I knew what was wrong with him, what his problem was—I articulated it, I framed it, I asked for services, I handed them the insurance card—every single one of their questions was addressed to him and not to me. No other twelve-year-old would have been in that position without a disabled parent there. That must have been really tough for him sometimes. And I know there were situations where his level of shame and sense of devaluation for having two disabled parents was really, really tough. It was tough for us and it was tough for him. I think we weathered that really well as a family, and I'm very happy about that, very grateful, but it was touch and go; it was a real struggle.

I think there's a real burden on families like ours. I don't know if it would have been any easier if he had had a disability. There probably would have been a whole host of other social problems that we encountered, but it was a really tough one, and it goes on. Now he has a wife from the majority culture who's had to learn a real fast course on disability, and that's interesting, and it's going well. We have one grandchild and we are acquiring another, and it's really fun to watch how children develop around disability and how they seem to regard it. Our grandson now is nineteen months old and for months he's been very aware of how wheelchairs work, always trying to grab the joy stick and engineer his way through the living room and around the rest of the world. And he—of course everybody knows, he has no innate fear of disability, but we wonder what comes ahead, what will he learn?

Cowan: They always will learn something that you didn't expect.

Gill: Well, I hope that this becomes increasingly a world where he can hang on to his wholesome view of human difference, and that's a real motivation for me to hope that the world does get a whole lot better on the issue of disability.

Cowan: Is that it?

Gill: I can't think of anything right now.

Cowan: Okay, we'll quit then. Thank you.

Kathryn Cowan

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In the 1980s, Kathryn Cowan was a job developer for a disadvantaged youth organization. She developed a program that brought youth together with senior citizens who served as mentors by sharing their personal and work histories. She subsequently served as librarian for HomeBase, the Center for Common Concerns, a public interest law firm that develops and supports policies and programs to reduce and eliminate homelessness.

She has a long-standing interest in political and social change, and followed closely the civil rights, antiwar and women's movements. In the early 1990s she became interested in the disabled persons' independence movement. In 1995 she was diagnosed with multiple sclerosis.

In 1997 she joined the staff of the Regional Oral History Office, The Bancroft Library, University of California, Berkeley, as an interviewer and editor for the Disability Rights and Independent Living Movement oral history series.

Kathryn Cowan has a B.A. in Communications from California State University Hayward.