

Regional Oral History Office
The Bancroft Library

University of California
Berkeley, California

Disability Rights and Independent Living Movement Oral History Project

Paul Longmore

DISABILITY SCHOLAR AND ACTIVIST, HISTORIAN OF EARLY AMERICA

Interviews conducted by
Ann Lage
in 2006

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 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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Paul Longmore, circa 2003
Photo courtesy Chris Rozales

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Thanks are due to other donors to this project over the years: Dr. Henry Bruyn, June A. Cheit, Claire Louise Englander, Judith Stronach, the Prytanean Society, and the Sol Waxman and Tina P. Waxman Family Foundation. The Bancroft Library's disability history program was launched with 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 agencies.

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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.

The project Web site (<http://bancroft.berkeley.edu/collections/drilm/>) includes the full-text of most of the completed oral histories. It 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 phases I and II 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 more than 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. Additional interviews on “Antecedents, Implementation, and Impact of the Americans with Disabilities Act” were completed for the project under a 2006 contract funded by DBTAC-Pacific ADA. Any of the views expressed in the oral history interviews or accompanying materials are not endorsed by the sponsoring agencies.

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Ann Lage, Project Director
Regional Oral History Office

The Bancroft Library
University of California, Berkeley
August 2007

Interview History—Paul Longmore

Paul Longmore, an historian of early America at San Francisco State University, was interviewed for the Disability Rights and Independent Living Movement oral history project to document his multiple roles for more than a quarter century, as a pioneering historian of disability, a leader in the development of disability studies, and an activist on disability issues.

Longmore, born in 1946, was the child of an evangelical Baptist minister. He had polio at age seven and underwent lengthy periods of hospitalization and rehabilitation as a child. He came of age in California in the era of historic societal battles for civil rights and against the war in Vietnam. Not until the late sixties and early seventies did he begin to think of his own experience of disability as comparable to the discrimination and stigmatization faced by members of other minority groups. His oral history examines the personal experiences and intellectual influences that shaped his thinking about disability during these years, as he was struggling to complete graduate studies and obtain an academic position.

During the 1980s, Longmore worked with Harlan Hahn and Carol Gill at the University of Southern California to develop an early disability studies program. At the same time he became part of a community of disability activists in Los Angeles, including Gill, Barbara Waxman, June Kailes, Douglas Martin, and others. Deeply involved in working against assisted suicide, he also combated disability stereotypes in the media and protested against work disincentives for people with disabilities in Social Security programs.

His oral history recounts his development as an historian of early America and a teacher, and the genesis of his interest in disability as both a subject of historical research and a useful category of historical analysis, like gender, race, or ethnicity. He reflects on the growth of interest in disability studies and critiques changes in the field, as social scientific policy analysis becomes increasingly eclipsed by humanistic studies, and scholars less connected with advocates in the disability rights movement. The oral history concludes with reflections on the public and private discourse about disability, contrasts between British and American approaches to analyzing disability in society, the complexities of disability identity, the impact of the ADA, and the implications of a disability perspective for the larger society.

Paul Longmore was interviewed at his home in an apartment complex adjacent to San Francisco State University, where he has taught since 1992. We met five times in September, October, and November 2006 to videorecord nearly ten hours of interview. The transcription was audit/edited by the interviewer and reviewed by Professor Longmore, who made only a few changes to correct the transcription and placed a brief section under seal until 2014.

The Longmore oral history was funded as part of a project on the antecedents, implementation, and impact of the Americans with Disabilities Act, with support from DBTAC-Pacific ADA Center. Additional support came from a generous gift from Professor Raymond Lifchez in honor of Susan O'Hara. Interview transcripts are available for research in the Bancroft Library and in the UCLA Department of Special Collections. Videotapes of the interview sessions are available for viewing in the Bancroft Library. Transcripts of this oral history and others in the Disability Rights and Independent Living Movement series are on line at <http://bancroft.berkeley.edu/collections/drilm/>.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Bancroft 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, The James D. Hart Director of the Bancroft Library, University of California, Berkeley. The catalogues of the Regional Oral History Office and most of the collection of oral histories can be accessed at <http://bancroft.berkeley.edu/ROHO>.

Ann Lage

Project Director and Interviewer

Berkeley, California

March 17, 2008

Interview with Paul Longmore
 [Interview 1: September 27, 2006]
 [Audiofile 1]

1-00:00:00

Lage: We are recording and today is September 27, 2006. I'm Ann Lage. I'm interviewing Paul Longmore, professor of history at San Francisco State.

Now, Paul, we're starting at the beginning; we're getting your evolution as a disability advocate and scholar, and as a historian. So let's start with your family, where you were born, and the things that you think are most pertinent.

1-00:00:27

Longmore: Yeah. Well, I was born in New Jersey. My father was a Baptist minister, and so we moved quite often, every three to five years when I was growing up, and eventually came to the West Coast, to Southern California. I mostly lived up and down the West Coast.

1-00:00:47

Lage: Why so many moves?

1-00:00:47

Longmore: Because typically Baptist pastors stay in a local church for a limited period of time. And with us it was, you know, three to five years each place. So—well, a couple of consequences for me: one was there are a lot of expectations put on ministers' children to be role models and to be examples and to be leaders, and-

1-00:01:21

Lage: And to be good, I would think.

1-00:01:22

Longmore: And to be good, yeah. Although in my case, my dad always encouraged me to think for myself, to think critically. He was kind of a maverick, himself, who went his own way a lot in his thinking and his activities. And not that he was some kind of troublemaker or something, but he was just an independent-minded person. And so from an early age he encouraged me to disagree with him and not just swallow accepted dogma. So I guess I was a little bit troubling to, say, some Sunday school teachers, at an early age because I would make points or ask questions that they weren't used to hearing.

When I got polio, I don't think that my post-polio disability then caused my parents' expectations for my life to change in a significant way. It seemed to me that what they wanted, their ideals for me, had to do with things I was still quite capable of doing. I mean, they wanted me to be a certain kind of person, a certain kind of Christian; to be obedient and faithful to what they thought God wanted me to do. And they always had this sense, which I guess is

generally kind of characteristic of preachers' kids, but also of first-born sons, that I had some really important things to do with my life.

1-00:03:03

Lage: Sort of a sense of mission.

1-00:03:04

Longmore: Yes. A sense of mission, very definitely. I mean, we were evangelical Baptists so in a lot of ways we felt that we were part of an outsider group, you know, culturally kind of marginalized.

1-00:03:23

Lage: You felt that in the community?

1-00:03:25

Longmore: Oh, yeah. I mean, in school, for instance in high school, and college, my friends were guys who were not religious. They were really smart; they were the intellectuals, they were the activists, and they just couldn't understand why I would believe the things I did at that age in my life. It just made no sense to them. And I remember when I was first a teaching assistant as a graduate student, I had a kid who was an ex-Catholic, and he was really hostile to religion, and when he discovered that I still, at that point, was religious, he was just shocked, he was just amazed. He kept saying, "You're so smart, I can't believe this. I can't believe you can believe that stuff." So I experienced that a lot growing up. So even before I became disabled, and then while I was both disabled and an evangelical Baptist growing up, I felt marginalized, and like an outsider.

1-00:04:32

Lage: Did your parents talk about—I'm setting the disability aside, for now—but did your parents talk about being marginalized?

1-00:04:37

Longmore: We had a sense of—our duty was to be witnesses. My dad's view was—the primary focus of his ministry was what's called evangelism, trying to convert people. I always felt uncomfortable trying to do that because I was kind of shy, and I also had a rather more complex view of life and the world, I think, than that perspective. It wasn't so simple as, you just get people to make a decision for Christ, and then their life is hunky-dory. But there was a really strong sense of mission and expectation that if you're doing and living the way you ought to be, it's likely that you'll be mistreated and even persecuted, and so there's a sense of not belonging to the world as it is. One of the gospel hymns we sang was "This World Is Not My Home, I'm Just Passing Through."

1-00:05:45

Lage: And maybe drawing some strength from feeling discriminated against.

1-00:05:47

Longmore: Oh, yes, absolutely. And you're part of a community of people who share those beliefs. Although I was also often kind of marginalized within the community and at odds with it, partly from becoming disabled, but also because I always had certain kinds of interests and sensibilities, politically and intellectually, and culturally. I mean, in a culture—the subculture I grew up in was, frankly, anti-intellectual in a lot of ways.

1-00:06:19

Lage: But you say your father did promote critical thinking. It doesn't seem to sort of go together.

1-00:06:23

Longmore: Well, there are contradictions there, yeah. That was one of the tensions between him and me. And he didn't share my interests, but he also didn't actively try to suppress them, either.

1-00:06:36

Lage: Politically, where did they stand?

1-00:06:39

Longmore: Well, one of the things I admired about my folks was they—I mean, they came from a very conservative background. Much more conservative than what they raised me in. They were fundamentalists, initially.

1-00:06:49

Lage: Were they from the South, by any chance?

1-00:06:50

Longmore: No. They were from New York. They were fundamentalists who evolved to become evangelicals. To the people outside evangelical Christianity, evangelical Protestantism, this may not make sense, but there really are significant distinctions between fundamentalists and evangelicals. And they evolved to become more open, and—well, in 1960, my dad was against the election of John F. Kennedy because he was Catholic. When we were kids in the fifties, my sister and I were not allowed to go outside and play on Sundays. But my folks changed. And in fact, in 1972, I campaigned for George McGovern and my dad was going to go along with me, and then he got really kind of disgusted with the screw-ups in the McGovern campaign, and he said, "I think I'm going to vote for Dr. Spock." And I heard myself say to my dad, "Don't throw your vote away. Make it count." You know, so that—

1-00:07:57

Lage: Well that's quite an evolution.

1-00:07:58

Longmore: And then I found out later on that my folks ended up having pretty liberal views about abortion, which surprised me. And that was very unusual.

1-00:08:08

Lage: Now what—I don't want to dwell too much on this unless it's important. Excuse me, I interrupted about abortion. But what did evolving to evangelicalism mean?

1-00:08:19

Longmore: Well, it's less rigid. It has a different view of the Bible than fundamentalists. It's not a literal interpretation of the Bible. It's more open to cultural differences. It may be a bit less rigid morally.

1-00:08:36

Lage: Is it also more wanting to convert people?

1-00:08:39

Longmore: Not more. But that's still certainly a major emphasis.

Anyway, I felt, in retrospect, that after I got polio and acquired a disability, in terms of what my parents expected, the kind of man they wanted me to be, in terms of service to God, and service to people—being of service is really big in this Baptist subculture. So, what are you going to do with your life that's going to count to help people? They weren't into political or social reform. They were into caring for other people. So at an individual level, that kind of concern, that kind of compassion, was a big part of their expectations. And I think I retained, and retain, some of the fundamental imperatives that your life's supposed to count for something, and to be of service. The specifics of how I do that is very different from what they had expected. But, you know, having a disability didn't change that. You can still be a very spiritual, moral, caring, serving person.

1-00:09:55

Lage: Now, when you got polio, and I want to talk about that more, did they see this as something God sent?

1-00:10:01

Longmore: They were told at the time, they were asked at the time, "What's the sin in your family?" But I think they knew better than that. One of the discussions that we often had when I was growing up was not specifically about *my* getting polio, or *my* disability, but more about how do you account for the reality of suffering and evil in the world? Theologically, how do you explain it that way? I hadn't thought of it until just now, but that was a frequent topic of discussion.

1-00:10:34

Lage: A discussion around the dinner table?

1-00:10:34

Longmore: Yeah, yeah. I mean, every night at dinner we would sit and talk about all kinds of things. We didn't talk about my getting polio because my dad always felt really guilty about it. He felt he was to blame. And I wish we could have talked about it because I certainly didn't feel that. He never got over that.

1-00:10:59

Lage: Now why did he feel he was to blame?

1-00:10:59

Longmore: He had disobeyed God in moving to Southern California, from Pittsburgh. And I said to him, when I finally discovered this, I said to him, “So because you didn’t do what you were supposed to do, God took a little kid and he made him get polio? I don’t know what kind of God you believe in.” But he would never really talk about that at any great length with me. Which is unfortunate.

I realized later in adulthood that my mother had, if anything, even higher expectations for what I ought to do and be than he did. So, they were pretty intense expectations.

1-00:11:44

Lage: Right. Did you have siblings?

1-00:11:45

Longmore: I have a sister who’s two years younger, yeah. I think the other significant thing in terms of my family dynamic is, I got polio at the age of seven, and I, again in retrospect a long time later, I learned about how boys get raised and their relationships with their mothers. And in American cultures, apparently at about the age of seven there’s a tendency, a pattern, among American mothers to start to distance themselves from their sons emotionally. They are supposed to become self-contained, emotionally self-sufficient men. Well I got polio at the age of seven, and necessarily my mother couldn’t distance herself—well, I guess she could’ve, but she didn’t. We, if anything, got closer because once I came home from the hospital, my mother was the person who primarily assisted me with all kinds—I mean, things that by the age of eight or nine I would have been doing for myself, she was doing for me. And we continued to be physically, and as a result emotionally, very close until I left home at the age of twenty-three, I guess it was. And over time, she would confide in me. She would tell me everything that was going on. I was, I think, her main confidant. And the consequence of that for me was twofold. One was it promoted a tendency I already had to be introspective, and to deal and want to deal a lot with emotions, internally and in relationships. And it also made me a lot more open to emotional intimacy with women. So most of my close friends have always been women, rather than men.

1-00:13:59

Lage: So you would talk about things differently than you might have with your father?

1-00:14:05

Longmore: Yeah. So that was another result.

1-00:14:06

Lage: Were you close to your sister?

1-00:14:10

Longmore: No. Not then. And I think that one of the unfortunate things for her was that during a period of several years when I was in the hospital, and then back home, and then back in the hospital again, she didn't get the kind of attention she needed there.

1-00:14:28

Lage: She didn't have that connection with her mother, maybe.

1-00:14:29

Longmore: No. No, she didn't.

1-00:14:33

Lage: Economically, how well off was your family?

1-00:14:37

Longmore: Our family was middle-class. My parents were certainly better off than they had been growing up, although they had never been poor. The kinds of churches that my dad initially was pastor of, in Pittsburgh, and then in Southern California, were white, upwardly mobile, middle-class people. These were families that came out of World War II, out of the Depression and World War II, and a lot of them migrated to Southern California after the war. And they were moving up, they worked in the aircraft plants there, and, again I didn't realize it until much later, there was a really strong emphasis in those churches on how you do social events. There was a lot of socializing. Our social life was built around the church. And a lot of it had to do with doing things appropriately and properly. And I realized in retrospect that my parents were kind of social role models for proper middle-class etiquette and style. And they were, at one level they were showing these people that came from working-class and poor backgrounds how to do things right. I can remember my folks saying about events that we had at the church, "That was done properly. That was done right." And that was one of the functions of that religious subculture.

1-00:16:29

Lage: Where were you living when you got polio?

1-00:16:33

Longmore: I was in L.A.

1-00:16:35

Lage: In Los Angeles proper?

1-00:16:36

Longmore: Yeah. We were right in L.A., and I was initially hospitalized at County General Hospital, and then did rehabilitation at Rancho Los Amigos rehabilitation center, which in 1953, when I got polio, was still a much smaller center than it became. They were just in the process of expanding it, and in fact we had to wait several months to get out of the acute care facility to go to rehab because they were building whole new buildings at Rancho Los

Amigos. And Rancho was in the process of becoming one of the major orthopedic rehabilitation centers in the world.

1-00:17:20

Lage: Were they responding to the polio [epidemic]—?

1-00:17:22

Longmore: Yeah. The March of Dimes was putting a lot of money into places like Rancho Los Amigos, so it was primarily polio rehabilitation, and later it expanded into other things. But in the 1950s there were a lot of people who had polio.

1-00:17:37

Lage: Do you want to talk a little bit about your experience of getting polio, and then the rehab?

1-00:17:43

Longmore: Well, my elementary school teacher, I was in second grade, said, in retrospect, I had been listless for some weeks which was unusual because she said I'd always been so alert. I got flu-like symptoms this one weekend. On Sunday night, I got up and I vomited in the toilet, and I told my mother, "My legs feel really short." The next morning I woke up sick, and my left arm was very weak, and I went into her bedroom and I said, "I can't put my sock on. Can you put it on for me? My left arm doesn't work." And so she put me to bed, and she called the doctor, and he said, "It's polio." So they admitted me to County General that day, that Monday.

1-00:18:35

Lage: Had you been aware of a polio epidemic?

1-00:18:36

Longmore: Yeah, and in fact a couple of weeks earlier I had said in a family conversation, "I bet I get polio?" And I'm not sure why I said that, but this was one of the last of the epidemics, because the Salk vaccine came a year and a half later. So every summer there were these big polio scares. So I was admitted to County General Hospital and within five days I was delirious, I was completely paralyzed from the neck down, I was put in an iron lung. I don't know how long that lasted, probably a couple of weeks. And then, after that, there was more than a year of rehabilitation.

1-00:19:16

Lage: But you weren't in the hospital?

1-00:19:19

Longmore: Yeah. All in the hospital. I was in an iron lung for a whole year before I was weaned from it. And, you know, they do these exercises in which, to try to get your respiratory muscles functioning again, they turn off the iron lung for five seconds, and you have to breathe on your own. And if you've got any residual muscles, they're going to try to work. But they don't want to over-tax them, so they do this for five seconds today, ten seconds a couple days later, and

then, you know, half a minute, a minute, five minutes. They very gradually build you up. And finally when you're able to be on your own, breathing on your own for several hours, then they start doing things like getting you up. So, get you back on your feet. And the first time they got me up, my legs collapsed underneath me. And all this is also assessing to see where you're going to get return. One day I was lying in the iron lung, and I'd been paralyzed from the neck down. All of a sudden, both of my legs jumped at once. And that was the beginning of the recovery of my legs. I mean, my legs were still very weak, but it was an indication that I was going to get some return there.

1-00:20:39

Lage: And I guess they don't really know why some people get return [of function].

1-00:20:41

Longmore: Well, you know, the polio virus attacks what are called the anterior horn cells of the motor nervous system. These are cells that come off the spinal cord. And they destroy some or all of them, and depending on how much they destroy, that indicates how severe or permanent your paralysis would be. What's remaining tries to take over for the destroyed cells. So after about a year, after twelve months, literally twelve months, I was breathing on my own virtually all day. Not in the iron lung, only sleeping in it. And then the next step was you go overnight. And if you go one night, then you're out.

1-00:21:25

Lage: Was that a little scary?

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Longmore: No, not really. I was really eager to do that. I was going home on weekend passes soon after that, and I really hated the hospital. I really, I was so miserable there, and I wanted to go home permanently. But the typical pattern, probably because they had a lot of money for rehab from the March of Dimes, was you stay there for three or four years, and do as much rehab as you can. And I, I guess just after a couple months of going home on weekend passes, I talked to the doctor, the head orthopedist, and I wanted to know when I was going to go home permanently. And he said, "You can go home after New Year's." So this was fourteen months after I contracted polio.

1-00:22:21

Lage: So you were eight, and you were already telling him—

1-00:22:23

Longmore: I was eight and a half. [Lage laughs.] And I went home for that Christmas and New Year's of 1954-55, I came back to the hospital beginning of January '55, and he reneged. And I was a very timid kid. Other kids threw tantrums, I never did. There were things I wouldn't do. I wouldn't eat cottage cheese. That was one of the things I really hated about the hospital, the food was just horrible. And I was a finicky eater anyway. I wouldn't go into hydro-therapy because I was really terrified of water, of drowning. And so I just wouldn't

cooperate with that. But I didn't throw any tantrums. I just became intransigent. So when he tells me, they tell me, "You're not going to go home," that was it. I became completely uncooperative. I never heard of Gandhi, but I practiced passive resistance. And they, for the first time since I contracted polio, they had me go see a psychologist in the hospital. For the first time.

1-00:23:36

Lage: Because you resisted.

1-00:23:36

Longmore: Yeah. And then they called my mother, and they said, "Is there a problem at home?" And she said, "No." Well, "What's wrong with Paul?" She said, "Well, he hates being in the hospital." And she's talking to the head orthopedist. She says, "And you told him he could go home. And now he's really angry at you because you're reneging on this." And the doctor said, "Well, we can't do anything with him here. We might as well send him home." So this was two weeks after I came back. And that afternoon she came out and collected me. And they said to me, "Okay, we'll let you go home if you promise that a physical therapist can teach your mother how to do physical therapy." And I said, "Sure."

So I went home and a PT came out. He trained her how to do the stretching exercises which were painful and I hated those, too. And after the last training, he left, and I said to her, "You're never going to do that to me again." And she said, "But you promised them that you'd let me do physical therapy on you." And I said, "Well I had to get out of there." [Both laugh.]

1-00:24:48

Lage: In retrospect, were those exercises important?

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Longmore: Oh, they probably would've helped with some things. When I was well into adulthood I started doing some exercises myself, but I think most of what they wanted me to do was, it would've had some advantages, but it mostly was focused on muscle-stretching. They were really afraid of muscle contractures. And I have found that that did not make a whole lot of difference to me. Later on, there were other things they wanted. Occupational therapists had devices they wanted me to use. One was, there was an orthopedic device that held up my right arm, called a "swivel feeder." It's to hold your arm up when you can't hold it up yourself, so that you could feed yourself. And it's got this kind of trough that sits under your forearm, and then a bracketing system that goes from underneath it and anchors to a body brace on your torso. It's hard to describe. Anyway, I was able to feed myself and write using that. But they also wanted me to use my left arm. And I said, "My left arm's completely paralyzed, my hand's paralyzed." "We'll put a prosthetic hook under that hand", and they ran a wire up my arm and down my side so that I could open and close the hook with my left foot. And I said, "Well, I don't have any

shoulder muscles that work in my left shoulder. I won't be able to control it at all." So sure enough, when I had that thing on, I couldn't control it so it would swing that hook right in front of me and block my right hand, so I couldn't use my right hand either. So, you know, I tried it for a few times, and then my mother and I agreed that this was useless. Well, that got us labeled as uncooperative and resistant.

The bigger issue came seven years later. We were living in Portland, Oregon, and an occupational therapist there, I was in ninth grade, she said, "You need to learn how to dress yourself." And she used really important psychological leverage with a boy of that age, a fourteen-year-old boy. "Only babies have their mothers dress them. You don't want your mother dressing you." Now, well, I didn't want to be a baby. So for several months, I tried dressing myself. And she had me trying to use button hooks which didn't work. I managed to get my shirt on. I managed to get most of it buttoned, I couldn't button the right cuff, because I couldn't use my left hand. I managed to get my pants on. I could get one sock on, but not the other. There were still things I couldn't do. And all this took about a half an hour, and it was really tiring. And after a couple months of this, I said to my mother, "This seems like a waste of my energy, and time. I need to go to school and study, and I'm exhausted before I get there." And she agreed. This again indicated that we were uncooperative and resistant.

But the interesting thing is that, what we had decided on ourselves was really implicitly fundamental principles of what would become the independent living movement years later. Which was, you use your energies for the most important tasks you have. You have other people assist you with things you have difficulty doing or can't do. And most important, you decide for yourself what's in your best interest. That's what we had—and I think a lot of other people with disabilities had come to those conclusions, themselves. But it really made us kind of rebels. And, bless her heart, my mother was really wise about stuff like that.

1-00:28:49

Lage:

And it is interesting that you had to have the permission of the doctors to bring you home. And it's not as much a feeling that your mother could say, "Okay, I think it's time."

1-00:28:58

Longmore:

No. Well, you know, one of the problems I had with my folks was they always yielded to the doctors' judgment. They respected the medical authority. And I, very early on, became really skeptical of it. When I was a senior in college, a history major, I took a course on the American Revolution. And a new book came out just then, called The Ideological Origins of the American Revolution [The Ideological Origins of the American Revolution, Bernard Bailyn]. And this book, which is a classic now, talked about how the revolutionary generation inherited an ideological tradition that was really suspicious of

power, that power is very dangerous. People who have power tend to abuse it, and it tends to be corrupting, so we need to hedge power about. And there were some people who thought the American revolutionaries were kind of paranoid. I read this thing and I thought, “Oh, yeah. That’s exactly the way it is. I know because that’s what I experienced.” [I experienced] people with excessive power in medical settings. So one of the consequences of my experience—well, I should tell you some other things that happened that set the stage for this. First of all, my parents acquiesced very much to what the doctors said, to medical authority. This came back to haunt us when my mother was dying of cancer, because they, again, did the same thing, and they should’ve questioned her doctor. It might have saved her life. And so here I was in my early forties going through the same thing, but in reverse now. It’s now my mother who’s the patient instead of me, and I want them to question the doctors a lot more, and they’re not. And I think that this is really dangerous. Anyway, when I was a kid, when I was eleven, I had major spinal surgery. I had scoliosis with polio. What they said at Rancho Los Amigos was, “Kids who get into the early rapid growth stage of early adolescence, the scoliosis radically worsens often times. And it can even kill them because the spine can collapse on itself. So we need to do something. We need to do some kind of radical intervention.” So they came up with a spinal fusion that virtually fused the entire spine. And they wanted to do that on me. And I’m glad they did. It saved my life.

1-00:31:42

Lage: You’re glad they did, you say?

1-00:31:42

Longmore: I am glad they did it. It took a year out of my life. I was in the hospital for half that year. It was quite an ordeal, I mean, I was in, at one point, in a cast from my knees to the top of my head. Before that I had this big metal framework around my head that screwed into my skull, and they tried to straighten out my spine with that.

1-00:32:02

Lage: Was this after the surgery?

1-00:32:03

Longmore: This was part of the surgery. They put you in this framework, and they would stabilize your body in the cast, and they’d pull your head up till they straightened your spine out, and then they would fuse it in that position in two or three surgeries using bone chips between your vertebrae so it would all grow together. They do the surgery differently now than they did then, so the reason I have the present spinal curvature that I have, that restricts my breathing and the reason I use the ventilator, is because in the early days of that surgery, they didn’t do it right.

1-00:32:44

Lage: Oh.

1-00:32:44

Longmore: Because they hadn't learned enough yet. But, nonetheless it saved my life.

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Lage: How do you know it saved your life?

1-00:32:49

Longmore: Well, in a couple ways. One is I think that they were right about what would've happened in adolescence, which is scoliosis radically worsening. The other is that even though this iatrogenic, doctor caused, lordosis, that's a forward curvature of the spine, restricted my breathing and made it necessary for me, starting in about eleventh grade to use a ventilator, the inadvertent result was that ever since about 1962, I've been using ventilator support for at least half a day, and in recent years most of the time, preserved my respiratory muscles. They don't have to work as much. And I think that's prolonged my life, and given me better health in lots of ways, whereas a lot of other people who breathed without any kind of respirator support for years experienced post-polio syndrome in middle age and had to start using ventilators with tracheotomies full time. And, I mean, I really think this turned out to be a kind of advantage, as hard as it's been.

In any case, back then when I was eleven, my parents knew how much I hated the hospital, and never wanted to go there, even for check-ups. They didn't tell me that the spinal fusion was going to happen. The night before I was to go in, and I was going to be in there for a half a year, I heard my mother whispering to my sister, and I ran out into the kitchen, and I confronted her, and that's how I discovered that I was going to have these, what ended up being four major surgeries in five months.

1-00:34:42

Lage: Interesting concept, which I experienced also as a child, of not being told about important things.

1-00:34:48

Longmore: But this was the worst of a good many examples of them not dealing with me directly, not talking to me about these things, not including me in discussions or decision-making.

1-00:35:01

Lage: Now, how old were you at this point?

1-00:35:03

Longmore: I was eleven at that point.

The consequence was I started to massively distrust them, and adults, and experts, and authority figures. I mean, take all these together, you know: "You should use the swivel-feeder on your left arm," "You should dress yourself," you should do this, you need that, we want to do this surgery. There were other surgeries I refused. "We don't include you," they don't say this, "We

don't include you in discussions about this, about your health and your life." I think a lot of kids who grow up with significant disabilities end up distrusting adults and authority figures and trusting themselves, and figuring things out for themselves. The kids I knew on that polio ward were very knowledgeable, medically, about their own conditions.

1-00:36:10

Lage: So they were getting the information somehow.

1-00:36:13

Longmore: Yeah. I think they were pretty—I mean, not that we had medical training, or anything, or professionals in any sense. But we learned enough. We learned a lot. A friend of mine who works at a hospital in the South Bay told me that one orthopedist there said she hated dealing with people who had polio, who are, of course, middle aged. And my friend said, "Why?" And she said, "Well, they don't talk to me like a doctor. They talk to me like I'm only a consultant." And I said, "Well, that's the way it ought to be."

And that carried over, I think. I don't think it's accidental that—well, let me back up. There's a particular polio subculture that came out of those rehab hospitals, of especially the postwar era. On the one hand, you got the message, "You're going to be able to do what you want to do. You're going to be able to live a life that you want to live. Look at FDR [Franklin Delano Roosevelt], he became president of the United States. You can do whatever you want."

1-00:37:21

Lage: So they told you this.

1-00:37:23

Longmore: I don't remember it being said explicitly, but I think the message was there. And it was there in the culture in general, too, because, you know, people who had polio were doing a lot of stuff.

1-00:37:35

Lage: Well, you—I've seen this in your writing, or somewhere, talking about overachievers, polio overachievers. And I wondered if there were any—

1-00:37:43

Longmore: Well, yeah. We were taught to be overachievers, you know. And that was part of the legacy of FDR. You know, you don't give in to this. You don't have to be a cripple, which meant more than physically limited. It meant being socially marginalized and dependent and unproductive. Overcoming meant you transcend not just your physical limitations, or any psychological restrictions you might feel, but any social limitations, too. You could do whatever you want to do.

1-00:38:11

Lage: Now, I'm wondering, if you could think about where that message came from. Did the occupational therapists give it to you?

1-00:38:20

Longmore:

I think one of the places where it developed, probably originally, I can't verify this with historical evidence, but I've seen some evidence to suggest that one of the places where it started was at Warm Springs [Georgia] because for a time there, when FDR was still alive, FDR and some of the polio patients really ran the show. And they developed this ethos of overcoming. And that's what FDR did. And I think then it got conveyed through the March of Dimes and other messages. It's very different from other diseases and disabilities. The expectations were very different. But then it definitely became imbued in the whole postwar ideology of medical rehabilitation that shaped what we experienced. So I don't think it was accidental that what happened was the postwar generation of kids who got polio then come to adulthood in the 1960s and we're coming in with expectations of what our life ought to be like, and then we discover that it's not going to be like that. But it's not because we're not trying hard enough, it's because there's prejudice and discrimination. We're simultaneously presented with the example of the African-American civil rights movement, and then the women's movement, and the antiwar movement, and other social change movements. And it's no accident that Ed Roberts and several of the other guys who were leaders at UC Berkeley in the 1960s had had polio. And others of us in other places had similar kinds of experiences.

1-00:40:03

Lage:

But you don't think that same message came to people who had spinal cord injury?

1-00:40:08

Longmore:

Spinal cord injury, yes. I think if anything carried that polio-overcomer rehab ideology into other disability groups, it was particularly people with spinal cord injuries. Not so much with some other disabilities. I don't think people with cerebral palsy got the same message, because it's typically congenital, and it also, if it has an effect on facial expression and speech, I think that causes other expectations that infantilize with cerebral palsy and some other kinds of disabilities.

There was another point I was going to make and it slipped my mind now. So we're witnessing these other movements, and some of us were very involved in those other movements. I started to follow the civil rights movement from about the time I was eleven, watching it on TV.

1-00:41:03

Lage:

Did you watch a lot of TV?

1-00:41:05

Longmore:

Yeah. A great deal.

1-00:41:07

Lage:

You couldn't have been quite as active after the polio.

1-00:41:08

Longmore:

I wasn't as active as I could've been and should've been, and I watched a great deal of TV, but I also followed the civil rights movement very closely, and then late in college I got very involved in racial justice and race relations issues as well as antiwar stuff on my college campus.

1-00:41:30

Lage:

Okay. I want to go into that. I just want to see if we've skipped anything.

I don't want to interfere with your report; I just don't want to skip over high school.

1-00:41:43

Longmore:

Oh, yeah. Sure. Well, one of the things that happened was I was in special ed classes. Well, I missed most of second grade.

1-00:41:52

Lage:

Now, were you in a chair, or were you walking?

1-00:41:54

Longmore:

No, no. I was walking. I've only had that wheelchair for about the last four years, now. I got polio in November of 1953, so I ended up missing the rest of second grade. I missed all of third grade. I came home late in what would've been third grade. I had a home teacher that was a waste of time. I got into a special education class in fourth grade, and was in that same class for the first half of fifth grade. Then I was back in the hospital for the spinal fusion, and missed the last half of fifth grade and the first half of sixth grade. And then I came back to that special ed class for the last half of sixth grade, and then late in that year I was allowed to go in the afternoons to a regular sixth grade class. And this was all preparation. Miss Gustafson, my special ed teacher for all three of those grades, had been in the school district in our town, El Segundo, which is right near L.A. International Airport, she had been in that district for decades. And she felt that I could make it in the junior high in our town. The word "mainstreaming," as far as I know, didn't exist as yet. This is now 1958. One other student who had had polio had graduated from our special ed class and gone on to the junior high school, was mainstreamed, and now he was getting ready to enter the high school. So Miss Gustafson persuaded—now that kid used crutches or a wheelchair, I forget. I was walking and just didn't have the use of my arms. Miss Gustafson used her influence and got the district to agree to admit me to the junior high school. And at the end of sixth grade I recall her calling me over to her desk one day and saying—Mike was the name of the kid who had gone on two years earlier. She said, "You and Mike have got to succeed. If you don't succeed, they won't give these other children a chance." Now, I've told that to a lot of people over the years, and they always say, "That was an awful burden to put on a twelve-year-old kid," and I never felt that. I didn't feel it at the time, and I haven't felt it since. I think, even now, I knew that that was right. That that's the way things were. And I did have a responsibility. She said, "You and Mike are pioneers." And I

had a sense of that. And from then on, through junior high, high school, college, grad school, I was either the only person with a visible disability, or one of two or three who I knew of. There were four of us in college.

1-00:45:11

Lage: Was the special education class a whole range of disabilities?

1-00:45:14

Longmore: It was a variety of all physical disabilities. There were only about six or seven kids in the class.

1-00:45:22

Lage: I wonder why they felt you couldn't just be in a regular class?

1-00:45:26

Longmore: I think they were probably afraid of the liability involved, and how they would handle it. One advantage I had over the other kids in my special ed class was I kept reading on my own. My dad had taught me to read when I was four, so I kept reading. So, in sixth grade I was reading at a high school level.

1-00:45:48

Lage: And you made up for all the class time you missed?

1-00:45:51

Longmore: Yeah, in terms of the reading. I never caught up with math skills. I was always behind in that, and so I didn't do as well in math or science later on because I missed so much of that. But the other kids were way behind grade level, and I think that was the really important thing for them because some of them were less disabled, physically, than I was. I think the result of their educational deficits was probably that they were never able to support themselves. So I went on to the junior high school, and the only exception they made was I got exempted from gym. So I had a study hall, and from then on I had a study hall in place of P.E.

1-00:46:36

Lage: Now, how did you get along with the other kids, and negotiate all that social scene?

1-00:46:41

Longmore: Well, the first year in junior high school, they made sure that three friends of mine from our church all had the same classes with me, except for, I think, the seventh period elective.

1-00:46:54

Lage: So they were making an effort to make this work for you.

1-00:46:57

Longmore: Yeah. They did.

And then, in eighth grade I guess it was, or was it the seventh [it was seventh grade], one of those two grades in the junior high, I had the only teacher I ever had who had a disability.

1-00:47:13

Lage: Who?

1-00:47:13

Longmore: Mr. Jeldum. Daniel K. Jeldum taught boys crafts. He had had polio. He walked with a very pronounced limp, and he was a very handsome man, and all the boys really admired him. And I spent so much time and energy on making things for his class. I mean, I got my dad to anchor a vise to this library table that we had in my bedroom, and I made things on that, holding them in that vise, and I really worked hard for Mr. Jeldum.

1-00:47:46

Lage: Did Mr. Jeldum take an interest in you, or discuss the disability?

1-00:47:51

Longmore: No. I don't recall talking about anything like that.

Decades went by. In 1988, this is now thirty years later. I was doing research at the Huntington Library in San Marino, and everyday I'd come to the library—I went there three days a week to do research on early American history—they would have a schedule. There's a sign-up place, and I would sign my name, and I'd look at the schedule. And they would list these visiting groups coming for tours of the Huntington Library and art gallery and botanical gardens. And this one day it said that an art class from El Segundo High School was going to be there, and the teacher was Daniel K. Jeldum. And I thought, "It's Mr. Jeldum! It's thirty years." So I went out to the front reception desk and I said, "When this group arrives, would you please have me paged?" And so they did. And I came out, and there's Mr. Jeldum, now white-haired. And he said, "I didn't recognize the name, but as soon as I saw you, I knew it was you." And we sat and talked for a while. And he said, "You know your father went to the principal about the work you were doing in my class." I said, "What about?" And he said, "Well, your father's rationale was, 'Paul needs to concentrate on academic classes. He's not going to be doing any manual labor, or any crafts. He's spending too much time on this.'" And I said, "He didn't realize why I was doing all that work. It was because of *you*. I wanted to be like you. I wanted to please you. I mean, I'm really kind of glad to know that he was thinking about my future, you know, and what I really needed. He just didn't understand that I needed *you* in a different way. And it wasn't really about crafts, it was about having an adult role model."

1-00:50:05

Lage: Interesting that your dad went kind of behind your back.

1-00:50:08

Longmore: Well, yeah. See, another instance of not talking to me. And, you know, in retrospect it was kind of pleasing that he was thinking about the future.

1-00:50:19

Lage: He was being activist.

1-00:50:20

Longmore: Yes. He was. When I was in high school my dad had gallbladder surgery. In those days, gallbladder surgery was major surgery, and he, you know, wondered if he would survive it, so he wrote each of us a letter. And the letter to me was basically, I guess, summing up his philosophy of fathering me. And basically, he said, "If I've been tough on you it's because I know that your life's going to be tough." And I thought—well, I don't know if I thought it then. But in retrospect, I think, "Well, yeah, tough, but in ways that I don't think he really understood. And I think you were mistaken in thinking that being hard and demanding on me was a way to help prepare me to deal with those hardships."

1-00:51:16

Lage: But he was hard and demanding? You hadn't really said that.

1-00:51:18

Longmore: Well, he was. I mean, he was very critical. They both were, both of my parents. Partly because he's evangelical, and high expectations of a first-born-son preacher's kid, there's that, too.

1-00:51:33

Lage: Critical of your behavior, or your schoolwork?

1-00:51:36

Longmore: Oh, everything. Really high expectations. When I was about ten years old—I was telling somebody this the other day—when I was about ten, one day I said to my mother, "You know, you and dad criticize me a lot, but you don't praise me very much." And she said, "Well, Paul, you've already got a swell head, and we don't want it getting any bigger." And I remember thinking, "You know, if I didn't have a strong ego, that might hurt me." [both laugh] So I really do have a swell head.

Anyway, along about seventh grade, about the age of twelve or thirteen, in there, I started to recognize that I was encountering condescending attitudes from people. And it took the form of realizing, one that adults didn't expect as much of me—

1-00:52:30

Lage: Like teachers?

1-00:52:30

Longmore: Teachers, anybody.

1-00:52:33

Lage: Except your parents.

1-00:52:34

Longmore: Except my parents. And that they also, outside my parents, didn't criticize me as much as they—I mean, it was like they were afraid to criticize me. It's like I was fragile. And I remember thinking, "I've probably been through more in my life already than you'll ever go through, and you treat me like I'm fragile?"

1-00:52:56

Lage: Interesting you'd have that perception.

1-00:52:59

Longmore: Well, from a very early age, I reflected on people's attitudes, and my feelings, and my reactions, and how they treated—I mean, I remember lying in the hospital when I was eight years old and staring at the ceiling, and thinking about what I was feeling about all this stuff.

1-00:53:17

Lage: Of course, lying in the hospital in an iron lung would make one more reflective, I would think.

1-00:53:23

Longmore: I would hope so. But I don't know that other people did that. I mean, I would sit there, and I would lie there and think things like this: "I feel anxious. Why do I feel anxious? What happened that made me feel anxious?" And I would trace back through the day and, "Oh, yeah. So-and-so said this, or they did that." And I was very introspective even at the age of like four or five. One day my mother came into the living room in our house in Pittsburgh, and I was kneeling on the floor in front of the sofa, with my face in the seat cushion, and my arms around my head, and she said, "Paul, what are you doing?" And I looked up and I said, "I'm thinking." So I was always that way.

So in junior high school I started thinking about these attitudes, and that I really didn't like them. And within a year or two, I found the word to describe what I was experiencing: prejudice. Probably as a result of my observing what was going on in terms of racial issues in America.

1-00:54:35

Lage: That was a word that was very common at the time.

1-00:54:36

Longmore: Yeah. And that's what I'm experiencing.

1-00:54:42

Lage: Even though it was sort of condescending. You seemingly were experiencing it more as condescension than barrier.

1-00:54:47

Longmore: Well, I thought it was devaluation, and I wouldn't have used that word then. I didn't know that word. But it was devaluation.

1-00:54:54

Lage: But were you thinking about barriers at the time?

1-00:54:54

Longmore: No. I was thinking about just how people perceived me. And I would say to my parents, "You know, so-and-so is prejudiced against me because I'm handicapped." And I would tell them what that person had said or done. They would say, "You're too critical," and, "People are nicer than that." And I would think to myself, "No, I'm right about this." I think they knew I was right. I think that they just didn't know how to deal with it. I think they were really afraid of it, and if they had said, "Yeah, it's true," and, "We all need to talk about that and think about how to deal with it. We need to just think about how we can resist that." But, you know, when I was growing up, there were very few people with disabilities who would've said that either.

1-00:55:52

Lage: And also, families didn't discuss things like that as much.

1-00:55:54

Longmore: No they didn't. And parents weren't encouraged to address that with their kids. There wasn't the same kind of advocacy. There was no disability rights movement.

1-00:56:05

Lage: But even outside disability, I don't think parents reflected as much with their kids about things like that.

1-00:56:09

Longmore: No. I think you're right.

So that was about the age of twelve, thirteen. I never met anybody who agreed with me about that until I was thirty-six years old.

1-00:56:24

Lage: That's quite a time period.

1-00:56:25

Longmore: Yeah.

1-00:56:26

Lage: And when would that have been?

1-00:56:29

Longmore: Well, thirty-six, that would've been--

1-00:56:34

Lage: Eighty-two.

1-00:56:34

Longmore: Is that when it was? Yeah, eighty-two.

What happened was, I was going through a divorce, and I was also struggling in grad school, and I decided I needed to talk to somebody, some kind of counselor, to help me deal with this stuff. And I went through a series of counselors, and each person I talked to, I realized more and more that disability was central to the various kinds of issues in relationships in my life, and I needed to talk about that. And nobody I was seeing understood disability. So I asked friends, a couple of friends, I had by now gotten involved in the disability rights movement in L.A., and I asked them if they knew anybody good, and they told me of somebody who was a psychologist with a disability. And I went to see her, and the first time I went there she said to me, "What did you want to talk to me about?" And I said—by now it was clear in my mind what it was—I said, "I think the biggest problem in my life is that people are prejudiced against me because of my disability." And she said, "You're right." And that was the first person who ever agreed with me. And I said, "I don't know if I can endure it." And she said, "You might not be able to." And that was such a relief because she wasn't saying, "You're not going to be able to do it. You're not going to be able to deal with it." She was saying, "Yes. It's that bad." And as soon as she agreed with me about that, I thought, "Okay, I can deal with this."

1-00:58:24

Lage: Oh, that's great.

[Audiofile 2]

2-00:00:00

Lage: Now we're recording again on tape two.

2-00:00:02

Longmore: Well, anyway, I went for all those years just having to trust my own judgment. And that's another good example of a kid, especially a kid who had polio, growing up with a disability, and you learn to trust yourself.

I sat in a meeting some years later, in the San Fernando Valley. There was a group of leaders in the L.A. disability rights community. And we could not agree on anything. And I looked at them, and I thought, "Everybody here had polio." And, you know, we're all rugged individualists. We were taught to overcome on our own, do it for yourself. But we also learned to trust our own judgment and not trust other people, and to be resistant to other people imposing their perspectives on us, and we don't know how to cooperate. [Lage laughs] We're a bunch of mavericks. How do you organize a group out of a bunch of mavericks?

2-00:01:11

Lage: That's funny. We were just talking before, while I was changing the tape, about the fact that I'm also from that same area, and you told me the story about El Segundo.

2-00:01:23

Longmore: You want me to say that again?

2-00:01:23

Lage: Because I want to ask you about encounters with that.

2-00:01:25

Longmore: Sure. Well, I lived in El Segundo, which is right south of the L.A. International airport in Los Angeles, and in the 1950s when I lived there, there was a sign on Main Street that said, "El Segundo: A White Gentile Community."

2-00:01:42

Lage: And it was aircraft industry and oil.

2-00:01:46

Longmore: It was a town that grew like a lot of Southern California, right following World War II. The aircraft industries were right there. Hughes Aircraft was there, Northrop was near there, Standard Oil refinery was on the south side of town, and a lot of the men in our church worked in those various factories. That's why they had come there.

2-00:02:08

Lage: Did you encounter that in your church? It sounds like it's the same social group that was in your church.

2-00:02:14

Longmore: Well, it's an entirely white town.

2-00:02:17

Lage: But the kinds of racial attitudes. Did that come up in the church?

2-00:02:19

Longmore: I'm sure it was there. I don't recall it at that point. I don't think I was old enough to be much aware of things. I can tell you this, that we moved up to the Santa Clara Valley—well, first we moved to Portland, Oregon, right at the beginning of 1960. And then in 1963, at the end of '63, we moved down to Santa Clara/Sunnyvale area in the South Bay. My dad was pastor of Santa Clara First Baptist Church. And right then, the Black Power movement started, and then I, as I said earlier, I had always, since I was about eleven, followed the civil rights movement, and now it was taking a turn. James Meredith marched across Mississippi, and the Student Nonviolent Coordinating Committee, SNCC, and the beginnings of Black Power was right when I was a junior and senior in high school, and starting college, 1964, thereabouts. And I was always disappointed with my dad because, unlike

other ministers, who were typically not evangelicals, he wouldn't join the civil rights marches, and I wanted him to.

2-00:03:46

Lage: So he didn't engage with that.

2-00:03:49

Longmore: He wasn't political at all. And I wanted him to, but he wouldn't do it. I mean, he didn't have to go south to do it, he could've marched in civil rights demonstrations in the Bay Area. But he just wasn't into that. And probably the people in his congregation wouldn't have accepted it either.

2-00:04:06

Lage: His congregations were mainly white?

2-00:04:07

Longmore: They were almost exclusively white, and they were pretty conservative politically. And so gradually, my politics were moving in a different direction. And one day, he and I were riding in the car on the 280 freeway, which was brand new then—I mean, Santa Clara Valley wasn't even Silicon Valley yet. That's how long ago this was. Sixty-four, I guess. And we're listening to the news on the radio, and there's a report about these Black Power activists in the south. And the story ended, and my dad said, "What do those people want?" And I thought. "Well, that's a really strange thing to say." Because what they were saying they wanted made perfect sense to me, you know, I really identified with that, very strongly. I hadn't yet made any connection, at least consciously, with disability issues. I started at Santa Clara University, as an undergraduate, and transferred from there in the middle of my junior year. We moved back to L.A., and I finished college at Occidental College, and then got my master's there.

Well, early in my junior year at Santa Clara was when I first started to think consciously about the connections, the parallels, between disability and race. And started to talk about it. But I didn't know how to talk about it.

2-00:05:52

Lage: Well, did you have a group of friends who had disabilities?

2-00:05:55

Longmore: No. I didn't know anybody with a disability.

2-00:05:56

Lage: So you didn't have a sense of community.

2-00:05:57

Longmore: And I wouldn't have wanted to know anybody with a disability at that point. I was trying to pass.

2-00:06:05

Lage: It's interesting, though, that without the group experience, you still began to see the parallels.

2-00:06:11

Longmore: Yeah. Well, because I was confronting these prejudices; I was experiencing them; I was struggling to figure out who I was; typical kinds of adolescent identity issues, or early-adult identity issues. But there's this added difficulty of what does it mean to be a person with disability, how do people perceive me? A lot of it had to do with romance, and dating, and sex. But there were other things, as well. Early in high school, after I realized, or decided that I was dealing with prejudice, I thought, I mean, I very consciously started thinking about, "How do I present myself to counter these prejudices? Well, if people think—if they expect less, if they think I'm mentally incompetent, intellectually not as smart, emotionally less together, not as strong as they are," and I also thought, "Then they probably think I'm sexually, somehow, screwed-up. Then what I've got to do is present myself in such a way to counter all that." And I heard this cliché about, you know, the first five minutes when you meet somebody determines how they'll perceive you. So I developed this style, now remember I was a pretty shy kid, I developed this style of when I met somebody I came on very strong. In the first five minutes, I was going to display my intellect, my wit, and my emotional strength. Going to get it all out there, so that at the end of five minutes--

2-00:07:52

Lage: You could relax.

2-00:07:51

Longmore: I said to myself, "If anybody is going to feel sorry for anybody else, it's not going to be them feeling sorry for me. It's going to be the other way around." And that's what I did.

2-00:07:59

Lage: How do you think that came across?

2-00:08:01

Longmore: Oh, I think I developed this very strong, powerful persona that impressed people and it--

2-00:08:11

Lage: It didn't come across as aggressive.

2-00:08:11

Longmore: Oh, it was aggressive. It was, at times, sarcastic, but it was impressive, and it was a little bit intimidating. Whatever it was, it wasn't pathetic, which is what I intended.

Years later, in my early forties, I came to the realization that it was effective, much more effective than I ever imagined or expected, but it was also rather limited in what it disclosed of me. I mean, when I taught at Stanford, I had a

colleague say to me, “You know, you’re pretty impressive.” And I thought, “Yeah, probably more than I realize. But what’s the consequence of that? What’s the result?”

2-00:09:00

Lage: Was he giving you a message?

2-00:09:02

Longmore: No. He was telling me. It was a compliment, he meant it as a compliment. Because he was a pretty aggressive guy himself. In fact, I said to him at one point, “You know, I realize, Steve, I don’t know if I can fit in at Stanford because people here have such an air of privilege about them.” And he came from a working-class background, his father was a labor union official. And he said, “Yes, they do. But you and I have something that they don’t have.” And I said, “What’s that?” And he said, “Rage.” And it’s true. It was really true.

2-00:09:39

Lage: So he saw that in you? Or did you see a correspondence [with him], as the outsider?

2-00:09:40

Longmore: Oh yeah. For different reasons it was there in both of us.

Well, I, from about twelve years-old on, it really enraged me that people would perceive me that way. I did not—I *still* don’t like it. I mean, I still, at times, have found myself trying to impress grocery store clerks by letting them know that I’m a professor. You know, I walk away and I say to myself, “What do you care? Why do you need to impress this person? You’ll never see her again, but you got to put that out there. You’ve got to get over this.”

2-00:10:15

Lage: It’s interesting that you have that much self-reflection.

2-00:10:20

Longmore: Well, you know, I’ve talked to a lot of people with disability, and I think a lot of folks, especially those who achieve a lot, have strategized how to go about doing that, and what the consequences are. And there’s a lot of self-awareness there.

2-00:10:39

Lage: One place I took you off the track was you were talking about your interest in race.

2-00:10:44

Longmore: Yes. When I was a junior at Santa Clara, I started thinking about it. I didn’t have a way to talk about it, so I began by joking. And this carried over to when I went to Occidental College, then, transferred that same year. I’d start out joking, and I’d make jokes about disability—well, the word was “handicapped” then. And I would tease some friends, who I knew I could get

away with this with. I would talk about, “Well, you’re prejudiced against me because I’m handicapped.” You know, and I’d make other kinds of jokes about handicaps. And didn’t realize at the time, but this was a way for me to start to talk about this stuff, you know, to introduce the subject.

2-00:11:35

Lage: Did it allow discussion?

2-00:11:38

Longmore: Well, no. Nothing serious. I mean, they didn’t know how to deal with it, and it was shocking. I had one friend in college, at Occidental, who was a refugee from South Africa, a black revolutionary who had been fighting in the underground. And he and another guy had run to the U.S., and they came to Occidental, and they became friends of mine. And this one guy, he could be very abrasive, and he would mau-mau people, and denounce any of us as white racists. It was a game we played, and one day he did this to me, you know, “You’re a white racist,” and he goes on like this, and when he paused I said, “Well, the only reason you’re saying this to me is because you’re prejudiced against me because I’m handicapped.” And he was just shocked. Nobody had ever turned the tables on him. And so we started to do that to one another. And I didn’t have a way to talk about it more seriously because there was nobody to talk to.

Actually, there was. There were three other students with disabilities at Occidental. Two had had polio, and one was blind. And this one woman who had had polio could’ve been my twin sister, she looked so much like me, I mean in terms of her bodily configuration. And I never associated with any of the three of them.

2-00:13:02

Lage: And there was no disability students group?

2-00:13:03

Longmore: No, no. Nothing like that. There weren’t even disabled student services programs at most colleges and universities then.

2-00:13:10

Lage: Now, when did you go to Occidental?

2-00:13:12

Longmore: I transferred in there, started January ’67, and graduated in June of ’68, and then stayed on for another two years to get my master’s. I got accommodations from teachers, but it was all individually negotiated, and there were probably other things I could have requested, but they didn’t even occur to me. There were no disabled student services on most college campuses in those days. The concept of reasonable accommodations didn’t exist. There were no laws at that point. It wasn’t until significantly later.

There were intellectual turning points for me about all this stuff. When I was a senior at Oxy, on my own, I picked up a copy of the book Stigma, Notes on the Management of Spoiled Identity, by Erving Goffman, a leading sociologist. And this book was published in 1962, and he had this sense, I mean, he had a really shrewd analysis of interpersonal relations, but he couldn't conceive of the possibility, basically said this, of stigmatized groups becoming politicized and having a collective identity and effort, a movement.

2-00:14:46

Lage: Did he entertain the idea and reject it?

2-00:14:48

Longmore: Yeah, he did.

2-00:14:52

Lage: And what kind of groups was he talking about?

2-00:14:53

Longmore: Well, the group he used the most to illustrate what he was talking about were people with disabilities, particularly physical disabilities. But he also talked about people with prison records, homosexuals, Jews. People with other, what he called, primal stigmas, like Jews; moral stigmas, that was criminality, or mental illness, or homosexuality; and then the physical disability group he referred to as people with "abominations of the body," which I love. Anyway, I read that book twice in two years, and I made a list of personal experiences that I could use to illustrate points he made, but he was talking mostly at the interpersonal level. As I said, he wasn't thinking of these as a political possibility—

2-00:15:49

Lage: But were you at the time?

2-00:15:49

Longmore: I did. I remember thinking at the time, "Someday we'll have a civil rights movement." And there I was, not wanting to associate with the other students with disabilities. I didn't know that up in Berkeley, and in a few other places, this is now 1968, there are other people who already collectively were starting to think about that.

2-00:16:12

Lage: We had the Rolling Quads already, I think.

2-00:16:13

Longmore: Yeah, they were.

Then when I was a senior, I guess it was just after I graduated from Oxy. One day I was in the library, going through the periodicals room, and here was the latest issue of the *American Scholar*. And on the front cover it had the title, I guess it was the lead article, Leonard Kriegel, who was an English professor at City University of New York, who had had polio. The article was entitled

"Uncle Tom and Tiny Tim." And I immediately sat down and read it. And this was another revelation to me. Again, he was not as political as I would become, but he saw the parallel between race and disability. He saw the reality of prejudice. He never carried it as far as my generation of activists would, but it was a starting point.

I talked to a couple people who are my age, who are disability activists who read that article too, and it had an impact on them. So that was, what, '68.

And then, another important intellectual turning-point for me came, I guess it would have been 1980, maybe '79, I haven't checked on that.

2-00:17:41

Lage: A lot later.

2-00:17:42

Longmore: A lot later. Yeah.

A book came out in 1980, called *The Unexpected Minority: Handicapped Children in America* by John Gliedman and William Roth. It's a classic, it's out of print. It was funded by the Carnegie Endowment for Education [Carnegie Council on Children]. It was a study of handicapped kids and schooling, but they went way beyond that. And it offered a totally transformative analysis, in terms of psychology, developmental psychology, in terms of education, in terms of the whole way you think about disability.

Well, at the time the book came out, there was an excerpt from their opening chapter, published in *The New Republic*, and basically it was a vision. What would a society look like in which people with disabilities were fully integrated? And what kind of society do we see instead? And I read this thing, and it was like describing life on two different planets. And that was another mentally transforming moment for me.

2-00:19:06

Lage: Have you ever met these people?

2-00:19:09

Longmore: Bill Roth. I got to know Bill Roth later on through correspondence.

2-00:19:12

Lage: This is not William Roth from out here?

2-00:19:16

Longmore: No, this William Roth is at SUNY Buffalo.

2-00:19:21

Lage: But did you get a sense of where—

2-00:19:24

Longmore: It is the William Roth who got his PhD at Berkeley, is that who you mean? He got his PhD at Berkeley, I think, in Poli Sci in the sixties.

2-00:19:34

Lage: I don't know. Where did their vision come from? Did they have experience?

2-00:19:37

Longmore: Well, Bill Roth has a disability. I don't know about Gliedman. Bill Roth went on, in the early eighties, to write a couple other pieces, that—"Handicap as a Social Construct" was another piece I read much later. But, anyway, those were major intellectual turning points for me. Well, I guess I ought to switch to another thing. I graduated from college, and my first year on my master's degree in 1968-69. And then in 1969, that summer of '69, I was now, what, twenty-three, I turned twenty-three that summer. I was still living with my parents. I hated it; I wanted to be on my own.

2-00:20:32

Lage: Did you have a vision about yourself?

2-00:20:36

Longmore: No, I didn't have a vision. There was no independent living movement then. They hadn't started anywhere in '69.

2-00:20:42

Lage: But when you looked forward, or your parents looked forward, what did you think they talked about?

2-00:20:46

Longmore: My parents never expected me to be on my own. My mother told me later, after I moved out, "I always prayed that you would get to be on your own, but I didn't believe it would happen, so I just assumed that I would have to help you for the rest of our lives." So here she was praying for this thing, and not believing it. So my mother and I, as I said, had been close. We couldn't get along now. I wanted to be an adult; I wanted to be own my own. She was going through menopause. So she was pretty volatile.

2-00:21:25

Lage: She probably wanted some time off, too.

2-00:21:26

Longmore: Well, I'm sure she did, you know. And, in fact, after I moved out, my mother got a career. A very successful one.

2-00:21:35

Lage: What did she do?

2-00:21:37

Longmore: She went to work for this Baptist, low-income housing ministry, and she became their expert on the regulations of the U.S. Department of Housing and

Urban Development. And when she finally retired, they had to hire two people to replace her.

2-00:21:49

Lage: Fascinating.

2-00:21:51

Longmore: So, it was really good for her when I finally did get away. But she, you know, before I left, she didn't want me to do that. And after I left, for the first several years, my folks were convinced I was going to die. They just didn't think—now, I lived on my own, with roommates. I got married, I got divorced. This is now eight years after I had left home. At least eight years. No it's more than that. No, it's thirteen years after I left my parents' house. So my mother says to me, "Maybe you ought to move home." And we're in my apartment. I said, "I am home. This is my home." She said, "Well, I know. But what if you can't make it?" I said, "Mom, I made it for eight years before I got married, and I'll make it again." And she said, "Oh, I know you will. But what if you can't?"

2-00:22:47

Lage: You have a message.

2-00:22:48

Longmore: That was their fear, always.

2-00:22:51

Lage: Did you ever have an attendant? In those days was that available?

2-00:22:53

Longmore: No. I had roommates. Well, I'll get to that. Let me backtrack to when I first lived on my own. In the summer of '69 I finally decided, "I've got to get out of here. I have got to get out on my own." I remember thinking, one day after a terrific fight with my mother, I thought to myself, "I either got to get out of here, or I got to kill that woman." [both laugh] You know. And I thought, "You got to get out of here." So I started to look for a roommate, and I couldn't find someone. And I finally gave up at the end of that summer, and I just didn't know what to do. I had no handles on how to do it. So one day, this—L.A. county had respirator technicians who would service the respirator equipment. The machine I had was the size of a night table. It was big. And this guy came out one day from Rancho Los Amigos Hospital, and he's servicing my respirator, and he says, "You know, Emma Saenz?" And I said, "Well, I've heard the name."

2-00:24:04

Lage: Say the word.

2-00:24:05

Longmore: Saenz. Emma Saenz. "You know Emma Saenz?" I said, "I've heard the name." Well, she was one of the people who had had polio, who lived in the county, about my age, a year older, I think, used a ventilator. He said, "Yeah, I just was servicing her equipment." Emma's from Mexico. Her father brought

her to L.A. after she got polio, because there was no rehab hospital in the rural part of Mexico that they lived in, and he left her at a rehab hospital in L.A. And she grew up at Rancho. She lived there for ten years. I didn't know that at the time, but that's what happened. He said, "She just got back from Mexico. She went down to visit her family. She traveled by bus. Alone. With her respiratory equipment and battery packs. And she asked strangers in the bus terminals to help her eat, because she didn't have the use of her arms. And to lug her equipment. And she traveled down there alone, and visited her family, and traveled back alone, and now she's back in L.A." And I thought, "If Emma can travel to Mexico, I can live in an apartment in Eagle Rock." So I started again, and I found somebody, I found a roommate. And I had three different roommates that first year, and then a group of roommates the next summer. And by the next summer, I was having a really hard time. I mean, this was tough. These guys were my personal assistants.

2-00:25:40

Lage: Did you pay them?

2-00:25:40

Longmore: I got In-Home Support Services money, and I got very little money, very little. So they were doing this because they were friends. Mostly people from my church, or people I knew at college. And it was a real struggle. I was learning how to manage people. My parents had not expected anything. I had to learn how to manage money. I had to learn how to shop, pay the bills, cook. You know, I would ask women to go out, you know, and I'd say, "We'll have dinner at my place, and then we could go to a movie." And they would say, "Well, I don't know how to cook." And I would say, "I do." And so I would buy some food, and we'd cook it together. So I'd learn how to do all this stuff, and it was still a real struggle, and the turnover in roommates that first year was quite a lot. So by a year later, I was thinking, "I can't make this work. This is just impossible." So one morning, one of my roommates comes in and he wakes me up, and he says, "The respirator technician is here to service your machine, and I said, "Oh, okay." And so I got up, and I'm sitting there with my pajamas on the edge of the bed, and he's the same guy, and he's working on the machine, and he says, "I just was over at Emma Saenz's place." So I said, "Oh, yeah. What's she doing?" He said, "She just got back from Europe." I said, "Really." He said, "Yeah, she went and studied in France for a year and then traveled through southern Europe. And now she's back here, and she's working on her master's at Cal State L.A." Well, I was starting on my PhD at Claremont that fall. And so, I said, "Well, if she can do that, I can do this."

2-00:27:38

Lage: But you never got together with her?

2-00:27:38

Longmore: Well, wait.

2-00:27:41

Lage: Oh. Okay.

2-00:27:41

Longmore: So, years go by, and it's got to be thirteen years went by, and every so often I hear about Emma. She got married to John Eivers. She had two kids. And I never met her, and one day the phone rings, and this woman says, "My name is Emma Eivers. I'm working on a PhD in Latin American Literature at USC." Well, I was teaching at USC by then. And she said, "I've been having a really hard time with the Department of Rehabilitation. They don't want to continue to fund my schooling, and I heard that you had fought them and won. And I was wondering if you would be willing to give me some advice. I was wondering if you would be willing to help me." And I said, "Oh, Emma. There is nobody in the world I'd rather help than you." [Lage laughs] So she came over and we chatted for an afternoon.

2-00:28:46

Lage: Oh, my.

2-00:28:51

Longmore: Yeah. So Emma was the one who kind of inspired me to--

2-00:28:52

Lage: She inspired you, but you never, until so many years later, get the idea of saying, "Hey, maybe I could talk to this Emma, and see how she does it."

2-00:29:05

Longmore: No, I didn't think of that. What did happen, though, was once I got out on my own, I did get in touch more with a network of people who had had polio and lived in the county, who all used respirators, and I forget how I met any of them, but there was one woman, in particular, named Mary Helen Fisk. She was a generation older than me. And I discovered that she and a number of other women in her generation had had polio in the late forties and early fifties, in L.A. county. They had gone to Rancho Los Amigos Hospital before it was a major rehab center. It was originally the county's poor farm. And they were all on one floor, and derelicts swept up off the street were on the floor below, and these guys used to come up at night, up the stairs and try to get into bed with these women. And some of them, many of them, their husbands left them, even though they had little kids, and these women were at Rancho for three or four years. And they finally went home, and they raised their kids, they lived on welfare, they raised their kids alone, they had personal assistants to help them through In-Home Support Services. I mean these were the first generation of people who really benefited from In-Home Support Services. And they really are the pioneers of independent living, even before the independent living movement. And Mary Helen was a leader among them. She was this strikingly handsome woman. Every time I saw her, she was nicely dressed, her hair, this lovely white hair was, you know, very well coiffed. And she was very strong, a very strong person. And I ended up coming to think of her as my disabled mom.

2-00:30:58

Lage: Now, when did you meet her?

2-00:31:01

Longmore: I forget how, but it was in the early eighties. And I was very young and very naïve, and very idealistic, and very moralistic, and I was struggling to learn how to deal with the bureaucracies. I mean, I had to deal with several bureaucracies: In-Home Support Services, Medi-Cal, the Social Security Administration, the Department of Rehab, all those. I mean, it can be really complicated. And I screwed up repeatedly, partly because I resented the whole system. I was defiant of it in ways, but also because I was ignorant, and kind of rigid morally about a lot of this stuff. And one day I remember, I had provided some information to one of these bureaucracies that got me into trouble with them. They were starting to question me pretty harshly.

2-00:32:06

Lage: Like what?

2-00:32:05

Longmore: I forget what it was, specifically. But it doesn't matter what it is, whether it's things that you've done wrong or not, they can still screw you up, you know, they can make mistakes. They don't know their own rules a lot. They can interpret the rules adversely to you. Anyway, whatever I did, I had myself in trouble. And they can put you through all kinds of hearings, and investigations, and they can cut you off.

2-00:32:34

Lage: It's like taking your life, in a way.

2-00:32:37

Longmore: Yeah. So, I mean, it's the stuff you have to depend on in order to live on your own. So I called up Mary Helen, and I said, this is what happened. And all I remember, I don't remember the details, I just remember her saying, "Why did you tell her that, Paul? Don't you know better than that?" And I said, "I know. I screwed up. Just tell me what to do." And she told me what to do. "Now, don't ever do that again!" "Yes, Mary Helen."

2-00:33:04

Lage: [laughs] Now I can see why you call her your disabled mom.

2-00:33:05

Longmore: She really lectured me. So I learned the ropes from people like her.

2-00:33:11

Lage: Before a movement, but a group of strong people.

2-00:33:14

Longmore: Well, the next step was in the late seventies. That would have been the early seventies, I'm sorry I said the eighties. The early seventies, I guess it was. Early to mid seventies.

In the late seventies I got involved more directly with her and a group of people, all of whom were respirator users who had had polio. There was a kind of gadfly named Richard Carman. A guy who had lobbied the board of supervisors of the county because he discovered that there are all these people, I mean there were about ninety of us in the county who used respirators, we had had polio, if we didn't live at home, the only place we were going to live was at Rancho Los Amigos Hospital, at a much greater expense to the county. So this guy had probably the one good idea in his life. He went to one of the leading supervisors, Kenneth Hahn, who was a really wonderful, humane man, with a really strong sense of justice, and he said, "You ought to give these people a supplement, a financial supplement, so they can stay in their homes." So all of a sudden, late in the seventies, we got this extra money. While everybody else used it to pay for personal assistants, I used it to hire a transcriptionist so I could dictate research notes, and that was a turning point in my graduate studies. I finally, after that, really started to blossom as a scholar, and my graduate studies became much more worthwhile. That would have been in 1975 that that happened. That was a big intellectual turning point.

Meanwhile, I get involved with this group. They formed what they called the Polio Survivors Association, and after a couple of years they asked me to be on the board. This is my first venture into any kind of advocacy. The only thing I remember about being a part of this board was I went to a meeting at someone's home, the home of one of the members, out in the San Fernando Valley, and this guy, Richard, who was the one who had lobbied the county, was dominating the whole thing. And all these people who had had polio, were just kind of finding it really hard to stand up to him. And, partly because they're all respiratory people, I mean they can't project their voices. There was one guy I remember who had had a tracheotomy that his vent was attached to, so he could get like three words out on a breath, you know, and this was a really smart guy, and he couldn't get a word in because Richard would keep shouting him down. And I just got really angry. And I've only totally lost control of my temper a few times in my life, but I did that afternoon. He got up out of his chair, he came and he leaned over to me and he tried to shout me down, and I rose up in my seat, and we were literally nose to nose, shouting at one another, and he broke. And I got up and left the room. I went in this woman's bathroom, and I closed the door, and I'm just heaving, you know, trying to catch my breath. I was so upset, and I thought, "What in the world did you do?" And I came back out, we left the meeting, and everybody was saying, "That was great, you stood up to him." That broke his power, and the disabled people took over that organization.

2-00:37:06

Lage:

Oh, he was not disabled?

2-00:37:09

Longmore: No. I'm sorry, I didn't make that clear. He was not disabled. They took over, and they ran that organization from there on out.

2-00:37:15

Lage: Oh, my. No wonder you had this sense of rage.

2-00:37:18

Longmore: Yeah. And after that—that was in the late seventies. Then around 1980-1981, I started to hear about people speaking, holding workshops in various places in L.A., and I started to go to these things. And that's how I got to know the leaders from the L.A. disability rights movement.

2-00:37:46

Lage: I'm thinking we shouldn't move to that today.

2-00:37:48

Longmore: Okay.

2-00:37:48

Lage: Let me just ask you about—it sounded as if this polio survivors group might have been the first kind of getting-so-close with other people with disabilities. Is that true?

2-00:37:59

Longmore: Yes, it was the beginning of my getting involved in advocacy.

2-00:38:05

Lage: Not just advocacy. I'm talking about identify with, not rejecting—

2-00:38:11

Longmore: Yes, connecting. Yeah.

It was the beginning of starting to talk to other people with disabilities. Most of these people were older than me. There were a few my age, they weren't so active. But I did start to talk to people in the late seventies, and I forget where else I might have had contacts, but I remember—

2-00:38:28

Lage: But, because you had said you kind of avoided it in school.

2-00:38:32

Longmore: Yeah. And I wasn't at that point. I mean, this was the first time I connected with them.

2-00:38:36

Lage: Did you have a problem inside with saying, "Okay, I'm going to be part of this group"?

2-00:38:41

Longmore: Well, I had misgivings because part of me had absorbed that overcoming ideology. Part of overcoming was you don't associate with or identify with

people with disabilities. You identify and associate with non-disabled people because you want to be accepted in the larger society. You don't want to be identified with stigmatized people. That was part of it. Another part of it was, and this especially came a little bit later when I really started getting involved with the activists. I mean, these people in the Polio Survivors Association were not really civil rights activists; they were focused on the specific concerns of that group. But a little bit later, I remember saying this to an acquaintance of mine, as I got involved with more activists I started to think, "You know, if this really is just a matter of me figuring out strategies for dealing with my individual life, I can do it, because I've been doing it. But if this is about social oppression, if we really are a minority group, then it's not going to be solved in my lifetime, and I don't know if I can face up to that." That was before I went to see that psychologist, and said, "Prejudice is the biggest problem in my life, and I don't know if I can deal with it." That was about the same time.

2-00:40:05

Lage: Well, let's save that for next time, the development of a minority group concept of it.

2-00:40:07

Longmore: One of the key things that started to happen in the late seventies was as I talked to more and more people with disabilities, I did start to compare notes with them; I did start to compare life experiences. And I started to realize that there were all kinds of things in my life that I had thought were strictly my problems, or my failures, that actually didn't originate with me, they were systemic, they were institutional. So I didn't blame myself for not making better progress or faster progress in my graduate studies, or that I wasn't getting as much out of my graduate studies as I should have. And I started to realize it's not because you're lazy. This is what's happening to a lot of other people, too. There's something wrong with the system of things. And that was, in a new way, a dawning of recognition that this really was social and political more than individual and private. I mean, I had said that in a way, earlier, but I think there's a progressive development of that idea.

2-00:41:28

Lage: It takes a long time for it to really sink in and hit you.

2-00:41:28

Longmore: Yeah. I mean you can say it in the abstract, but then, "Okay, I'm dealing with individual prejudice. Where does prejudice come from?" Well, it's not just individual, it's from socialization. But then you realize that there's institutionalized policies that restrict you, that limit you. That's when I started to realize that it's happening to more people than just me. That it ain't individual, it's social. Yeah. That was the key thing in the late seventies.

2-00:42:01

Lage: Okay, I think this is a good time to take a break 'till next time.

[Interview 2: October 4, 2006]

[Audiofile 3]

3-00:00:00

Lage: Now we're recording. It's October 4, 2006, and this is the second interview with Paul Longmore.

Paul, you said you had a couple things that you had been thinking about.

3-00:00:10

Longmore: Following up from our last interview, I wanted to say some more things about my parents that I think are significant. One of the things that I've been thinking about is that I'm interested about things my parents didn't understand, for instance, when I talked about disability prejudice and discrimination. One of the things it took me a long time to realize about them was that there was no one, or anything, at least that they knew of, that would help them understand how to raise a son with a significant physical disability, what they would have to deal with. I mean, in any respect.

3-00:01:01

Lage: No support systems of any kind.

3-00:01:02

Longmore: Not that they knew of. And I think they really struggled to know what to do. I'm not sure who they talked with, or may have talked with, but there were not support systems in place. Nobody in my family ever was encouraged, even, to get into some kind of counseling about this. So I think they had to try to figure things out pretty much on their own. In addition to that, and despite the fears they had for me or about me, when I decided on certain things like moving out, living on my own, this, as I indicated, at a time when there were no independent living centers, and there was no independent living movement, they didn't say "no." They didn't think it was going to work; they were terrified. I think the first several years they thought I was going to end up getting sick from something, and probably dying.

3-00:02:20

Lage: But did they convey that to you along the way?

3-00:02:23

Longmore: I knew they worried about it because I did frequently catch colds, and colds were very dangerous. And whenever I did, I would go on home to their place. This was for the first several years. Eventually I learned how to manage those things on my own. But they never said, "No, you can't do this. We won't support you in doing this."

3-00:02:48

Lage: Because you had shown that you were pretty strong-willed along the way.

3-00:02:52

Longmore:

Well, they—yeah. I mean, stubborn and difficult. Yeah. [Both laugh] Likewise, with regard to my professional and educational future, they didn't say, "You couldn't succeed in graduate school," or, "You won't be able to be a college teacher. You won't be able to be a historian." I think they had misgivings.

3-00:03:23

Lage:

Did they ever say what they did think you might be?

3-00:03:26

Longmore:

No. The interesting thing was the misgivings that they expressed had nothing to do with my disability. It had nothing to do with "no one will ever hire you." I mean, as you know from the stuff of mine you read, I had some college professors and graduate school advisors tell me, "No one will ever hire you. You should forget about this." My parents never said anything of the kind. Their bigger concern, I think, was—I came from a religious subculture in which the important thing in life was being of service to God and to other people. And I don't think they could see exactly clearly how it would be the case that teaching American history at the college level would be that kind of service.

My dad used to warn me when I was in graduate school, working on my PhD, "Paul, don't become an ivory tower intellectual." He just thought that was impractical, and not terribly useful, socially, I think. So I've always felt like there was this kind of anti-intellectual streak; that they just didn't understand that aspect of me. Of course, I also internalized a lot of that, so part of me has always felt like, "Well, in addition to doing scholarly work, I've really got to do something else that's really worthwhile."

3-00:04:59

Lage:

Is that an impulse to some of your activism?

3-00:05:01

Longmore:

Oh, yeah, I'm sure it is. And I never do enough of that. But then, I never do enough of anything.

3-00:05:07

Lage:

Right, of course.

3-00:05:09

Longmore:

But they never said, "You should quit school. You need to do something else that's more realistic." And they just consistently supported me in doing what I did.

3-00:05:24

Lage:

Well, that's validating.

3-00:05:26

Longmore:

It was. I mean, I never had any doubts that they would be there. For instance, I lived forty-five minutes away from Claremont Graduate School where I got my PhD, and for the first several years, when I was taking courses, my mother drove me there, and waited for me while I took my classes, and then drove me back home. And I wasn't living with them at the time. So that was quite something.

And then, even after I finished, I was doing research for several years at the Huntington Library in San Marino which was about twenty minutes to a half-an-hour from where I lived. And one of them, three times a week, would pick me up in the morning, and we'd drive over there, they'd drop me off, and they'd come back in the evening. I didn't have the money to pay drivers to do that.

[interview is briefly interrupted by a phone call]

3-00:06:40

Lage:

You were talking about your parents driving you. Did this give you extended time when you might have long conversations with your parents? Did you discuss life issues?

3-00:06:49

Longmore:

Well, my mother and I talked a lot. I mean, as I told you last time, after I came home from the hospital, from then on, we spent a lot of time together, and so—

3-00:07:02

Lage:

But even in your twenties—

3-00:07:05

Longmore:

Yeah. Into my twenties, when she was driving me to and from school, there were a lot—

3-00:07:11

Lage:

Did she talk about disability with you? Was it sort of an issue that they left to one side?

3-00:07:16

Longmore:

You know, I wasn't really talking about it that much. I was thinking about things. But later on, while I was still in graduate school, but this is now beginning of about 1980, in Los Angeles, when I started to get involved with the disability rights community there, and then I started to talk more, and think more, and I also got a lot angrier at that point. I started to get much more in touch with how angry I was about prejudice and discrimination, and began to get much more aware of what was happening to other people with disabilities, some of whom were really oppressed.

3-00:07:59

Lage: And you hadn't been that aware because you didn't know that many people with disabilities.

3-00:08:02

Longmore: Right. Now, I had some knowledge, but nothing like what I came to know later on. And I can remember at one point my mother expressing some concern to me about how angry I had become, because I'd become pretty militant about disability issues, and increasingly outspoken. And she said to me one day, she was concerned, but, "You know, when you were a little boy, people used to remark about what a great smile you had. You don't smile very much anymore." And I said to her in my kind of militant voice, "Well, I don't see that much to smile about." So I—well, I had also become politicized and alienated about a lot of other stuff a lot earlier, I mean, starting in the late sixties. But that was not about disability issues so much; that was about things like the Vietnam War.

3-00:08:59

Lage: Do you want to talk a little bit more about that? Did you get very involved in antiwar activities?

3-00:09:01

Longmore: Oh, yeah, I did. Once I got to Occidental College, where I transferred early in 1967, the middle of my junior year, then I really—that was a much more activist campus. Santa Clara University, where I had been before was pretty conservative. In fact, one of the first POWs in Vietnam was a graduate of Santa Clara, who was, I think, in the air force or navy. Anyway, I got to Occidental, and I got in touch with a lot of people who were politically very activist, and I got very heavily involved in race-relations issues on campus. I was on the Task Force on Campus Racial Attitudes; I was very concerned about race, because as I was beginning to realize, I really identified with issues that had to do with prejudice and discrimination.

3-00:09:55

Lage: But you still didn't have this minority group model in your head, it seems like.

3-00:09:57

Longmore: At that point I was beginning to think about disability as parallel to that. And I was beginning to say to myself, "Someday people with disabilities will have a civil rights movement of our own." But what I didn't know was it had already started, I just wasn't aware of it.

3-00:10:13

Lage: You weren't aware of Berkeley, yet, or Boston.

3-00:10:15

Longmore: Berkeley or anyplace else, because it was happening at other places as well. And I just didn't know about it. I didn't know people with disabilities. I also got involved in anti-Vietnam War issues, antiwar in general.

3-00:10:33

Lage: What kind of activity?

3-00:10:37

Longmore: My senior year at Occidental was a big year. This was 1968. The next year was even bigger. Between '68 and '70 was when a real transformation occurred for me. Sixty-eight was the year I graduated. It was also the year of the Tet offensive in January, Eugene McCarthy got into the Democratic nomination race, Lyndon Johnson said he wasn't going to run again. I campaigned for Gene McCarthy in the June primary, in California. The slogan was "Come Clean for Gene." I was so clean, I didn't need to clean up. I mean, if I had cut my hair, I would've been bald.

3-00:11:30

Lage: Okay, so you were not a long-hair.

3-00:11:31

Longmore: Not at all at that point. You know, there were urban rebellions in the black communities in a lot of cities. The Democratic Convention in Chicago. That week, my family was traveling across country, and we were watching the convention on TV in the motel rooms at night, and seeing the demonstrations and the police brutality and what was going on on the floor of the convention. Then, in restaurants, all across the country, we were hearing people in the heartland of America saying that police ought to kill those protestors.

3-00:12:15

Lage: Now how did your parents react to that?

3-00:12:16

Longmore: They were moving left. They had been Republicans, and they, by now, had become Democrats, liberal Democrats. And that summer radicalized me. It was also the year that the movie *The Graduate* came out. Well, Benjamin, the lead character, was a history major, and just graduated from college. And that was me. I mean, I really identified with him. This guy was confused and alienated. It wasn't about politics, it was about life. And in some way I really identified with him. Years later, that movie was on TV and I was at my parents' house, and I said, "Oh, I want you to watch this movie with me. This is the story of my life." And here's Benjamin going to bed with Mrs. Robinson, and my mother turns to me and says, "In what way is this the story of *your* life?" And I said, "Not *that*." [both laugh] "It's the feeling of alienation, Mom."

So there was that. And then the next year, I stayed at Occidental to work on my masters, and in '69, and '70, a lot of other things happened. Early in '69, we started to have teach-ins at Occidental that I was a part of planning and leading about military recruiting on campus. And I got very involved in that. And then the next year was Cambodia and Kent State, in the spring of '70. So I was involved in all kinds of antiwar protests.

3-00:14:00

Lage: There were also the riots in Watts.

3-00:14:03

Longmore: Oh, that was earlier.

3-00:14:05

Lage: Yeah. Was that '68?

3-00:14:06

Longmore: I forget what year that was. For a historian, I'm not very good with dates.

Anyway, I got involved in a committee to get the college to divest from companies that did business in South Africa. So I was into all those kinds of things in that period.

3-00:14:33

Lage: Were your religious views changing at this time, or did that come later?

3-00:14:37

Longmore: I was still very active, but increasingly questioning and alienated, having to do with the failure of evangelical Christians to deal with social justice issues. So at this point I re-thought my views of things like war, and decided that the only consistent practice would be to be a Christian pacifist. As I read the Bible, that seemed to be the necessary conclusion. I eventually turned in my draft card, even though I was 4F, and sent a really self-righteous letter to the draft board telling them why I couldn't even carry a—because I was still legally required to carry a draft card in my wallet. So I sent it back, and as I read the letter, years later, I thought, Oh, my God, you were an arrogant little self-righteous so-and-so.

3-00:15:36

Lage: But those were the times, too.

3-00:15:36

Longmore: Well, yeah. I mean, I think the position was right, morally, but there was a certain haughtiness about it that I would not like to think I continue to exhibit.

3-00:15:53

Lage: You said you had a couple of things you have been thinking about. Do you want to go back to that?

3-00:16:00

Longmore: Oh, yeah. I'll go back to that in just a second. In terms of my relationship to evangelical Christianity, I continued to go to various kinds of churches. I switched denominations from Baptist to Presbyterian, and then to another denomination called the Swedish Covenant. But that was not because of any change in theological beliefs, but because there were no single young women in the churches I went to, so I kept switching. And finally married a woman I

met at the third one of those churches. And after I got married, then I really got much more in touch with my alienation from the church.

All through the late sixties, and through the seventies, into the early eighties, I found myself having to fight with myself to stay inside the church, because I was really concerned about social and economic justice. And these were people who were apolitical, or anti-political, or politically conservative. The summer of 1972, one of my roommates and I went and lived in Chevy Chase, Maryland; his parents worked for the State Department. We arrived the day of the Watergate break-in, which I had nothing to do with. [Lage laughs] And I also campaigned for George McGovern that spring and fall. I took a semester off from my PhD to work on the McGovern campaign in the fall. And I more and more felt at odds with the evangelicals I knew. But I still, for another decade, I still continued going to church, and I eventually came to feel that not only were they off-base politically, and inconsistent politically, but in terms of spirituality and community, there was something severely lacking as well.

3-00:18:16

Lage: With the several churches that you went to.

3-00:18:19

Longmore: Yeah. But, you know, it's all extensions of the same general American evangelical subculture. And I knew some really wonderful people. In some places there was a really strong sense of community. This one Presbyterian church, there was a group of young adults in the college fellowship, and it was a really wonderful community for a while. But, you know, people get older, and they got married, or they left, or they went off to school, or something. And I got older, and didn't fit in with that group, so I went to this other church, and I didn't find the same community there, and finally, I just felt like, "You know, we're not even good at the things we claim to be good at."

3-00:18:59

Lage: Which is creating community, you mean?

3-00:19:02

Longmore: Yeah. I mean, I could see at this one church there were people there who were really struggling in their lives, and hurting, and I felt like we didn't really grapple with the real issues in their lives.

3-00:19:16

Lage: Did you discuss this with your father? I would think that would be—

3-00:19:19

Longmore: Yeah. I did. And finally, I just got bored, and I said, "You know, there are better ways to spend a Sunday." And so this is while I was still married, I quit going to church, which was very hard on her. And then after we split up, I never went back. Although, occasionally I would meet some woman I would date, and an awful lot of these women belonged to churches of various kinds. So they would say, "I'd like you to come down to my church with me." So I

said, “Well, I’ll visit.” So I would go, and I would listen, and I would say, “Ah, this is why I don’t want to be here.” There’d be something, you know, that it was a part of that alienation. So I guess, at this point, I would say, I retain some of the basic beliefs, in terms of God. The universe does not make sense to me without a God, and ironically, the reason is, “There must be a God because things are so awful.”

3-00:20:35

Lage: That is ironic.

3-00:20:35

Longmore: There’s something so out of kilter in this universe that there’s got to be some kind of ultimate resolution somewhere, and somehow. So there must be some kind of God. Otherwise, why would I feel like things are so wrong? Why would I feel so offended by the evil and injustice in the world?

3-00:20:54

Lage: Oh, I see. Where would your own sense of being outside of that come from, do you mean?

3-00:20:57

Longmore: And it’s not just me. I mean, we all have this sense that something’s wrong, and it ought not to be this way. If it’s just a gigantic mechanism, if we’re just biochemical robots, then why would we feel a sense of moral wrong? It doesn’t make sense to me that there’s some kind of simply evolutionary advantage to that, and that it evolved in some sort of non-theistic way. I mean, that doesn’t make sense to me. How could a robot have a conscience, or a sense of alienation?

Not that I’ve made sense of all of it. But anyway, so I retained that much. I jettisoned a lot of the doctrine, practically all of it that I grew up with. But a lot of the imperatives are also still there. I mean, the idea that I’m supposed to obey God and serve other people. You know the Minnesota Multiphasic Personality Inventory? A roommate of mine, at one point was a psychology grad student, and he took a class on testing and measurement, and he tested all the guys in the house. And one of them was the MMPI. And one of the questions is “Yes or No. I am on a mission from God.” And I read that, and I said to him, “Yes, but I’m not crazy.” [both laugh]

But I still feel a sense of that imperative. So I got into an argument one day with a grad student at Stanford when I was teaching there, and this guy was basically subjective in his approach to history. One interpretation is ultimately as valid as another. And I said, “So you mean, the Holocaust historians and the Holocaust deniers, their perspectives are equally valid.” And he said, “Well, no I don’t mean that.” I said, “Well, that’s the implication of what you’re saying. In fact, you can’t do history without some belief that there is, out there, an objective historical reality, whether or not we can reconstruct it. It’s not just subjective, and all of our historical interpretations are equally

valid. What we're trying to do is get some approximation of that historical reality. I might not use the word 'truth' anymore, but I would use the word 'reality.'" And in the midst of this argument with this kid I said, "My God. I'm still a Baptist."

3-00:23:28

Lage: Said it out loud?

3-00:23:29

Longmore: Yeah I did. I said it right to him. I said, "I can't believe this." So that has never gone away. I said to myself, "You can take the boy out of the Baptist Church, but you can't take the Baptist Church out of the boy." That seems to be the case.

Now, the other thing I wanted to tell you about that I had been thinking about was—I had mentioned, I think, last time about when I was in about ninth grade, an occupational therapist tried to teach me how to dress myself, and said, "You really need to be able to do this so you're grown up." Something else occurred to me that was even more significant. Soon after I left the rehabilitation hospital, they gave me this support for my right arm called a "feeder," to hold my arm up so I could feed myself. And I used that for years, up until 1972. And I would feed myself with a fork or a spoon. And what I didn't realize, until afterwards, was it was extraordinarily exhausting, physically, to do that. I never finished a meal. I would get to a point where it would just be too much effort, too much work. And I was also a finicky eater. But that became the explanation and the excuse that I bought into as well. My parents, even friends, who would get exasperated with me, would say, "You're such a fussy eater. You're just so..." I didn't like a lot of kinds of food. But I realized that a part of it was it was really hard work to feed myself.

3-00:25:19

Lage: It wasn't much fun.

3-00:25:24

Longmore: It was not fun at all. I only ate out of necessity. And I used to say, "I only eat to keep my brain going." It was impossible to enjoy it because it was such effort. It was so exhausting. And then the summer of '72, my roommate, Mike, and I went and lived in Chevy Chase, Maryland, with his folks. And his mother was really kind of insistent on helping me. And she wanted to help me eat. And she was so pushy about this that I kind of gave in to her. And I discovered something. I ate *more*. I finished meals. So I got back to L.A., and I stopped feeding myself. I started to have my roommates, who were also assisting me with other things, I started to have them help me eat. And I started to have other people, like when I would go out, they would assist me in eating, too. Now, this is the shocking thing about it. I was at this point, this is 1972, I was a year into my PhD program, I was twenty-four years old, and I weighed sixty-nine pounds.

3-00:26:40

Lage: No.

3-00:26:42

Longmore: I was malnourished. I was starving.

3-00:26:48

Lage: And nobody picked that up?

3-00:26:50

Longmore: They thought I was a fussy eater, and that's why I was skinny. In the first year after I'd stopped feeding myself, I gained twenty-five pounds. And I looked back, and I said, "How did I make it through high school and college, and into graduate school? How did I function mentally? How did I function academically? I mean, what might this have done to hold back my intellectual development?"

3-00:27:21

Lage: That's really striking.

3-00:27:25

Longmore: Well, this is what I was taught in rehabilitation: you need to be as independent, physically, as you can. And that includes feeding yourself. Babies get fed by somebody else; adults feed themselves. So I bought into that. The problem was I was starving. And in retrospect, I realize here's the best example of all about how some of what is imposed on people with disabilities in rehabilitation, or in special education, some of what's internalized by us, it has nothing to do with physical health. What it has to do with is cultural values. That's where that imperative comes from. It's an ideology, it's not an objective reality about maintaining good physical and mental health. Some years after that, I had a woman working for me who was also a teacher's aide in a special ed class. And she came to work one day, and she said to me that she had a ten-year-old boy in the class with cerebral palsy, and he wanted a stick of chewing gum. And she made him open the pack of gum and unwrap the stick himself before he could have it. It took him fifteen minutes to get that task done, but then he puts the stick of gum in his mouth. And she felt pretty triumphant at having taught him something important. And I got mad at her. And I said, "What was the point of that? I mean, that kid has limited physical energy. There are lots of other things that are really important for him to use that energy to do. Unwrapping a stick of gum and sticking it in his mouth is *not* one of the important things. A smart disabled person has other people to do those tasks for him or her, and saves their energy for the things that are really necessary for them to do." And by then, I was, of course, involved in disability rights and the independent living movement, and I had begun to absorb that difference.

3-00:30:00

Lage: And almost an ideology in itself.

- 3-00:30:01
Longmore: Well, it's a counter-ideology. Exactly.
- 3-00:30:05
Lage: How was it for you before there were sort of independent-living models and systems? How did it work to have friends take care of you?
- 3-00:30:16
Longmore: I had to figure out everything on my own until I started to meet people with disabilities after I started—I mentioned about Emma Saenz Eivers, and Mary Helen Fisk.
- 3-00:30:26
Lage: But how did it work to have friends act as your personal assistants?
- 3-00:30:32
Longmore: Oh, I see what you mean. Well, I got very little money in those early years. The In-Home Support Services funding I got was meager, and it really wasn't enough to pay anybody.
- 3-00:30:44
Lage: But there also weren't people to hire.
- 3-00:30:47
Longmore: Well, there were. Mary Helen had people who worked for her. No, there were people to hire. I was just getting really short-changed. I was getting fifty-five dollars a month for In-Home Support Services. And I required all kinds of assistance. It was dressing, and showering, and meal cooking, and housekeeping, and all that stuff. And, you know, assembling my respiratory equipment; the stuff I was using in those days was much more elaborate, and complicated, and cumbersome than the equipment I use now.
- 3-00:31:21
Lage: You needed it for life-sustaining activity.
- 3-00:31:23
Longmore: Yeah, absolutely. I mean, it took forty-five minutes to assemble it at night. Now the stuff I use takes ten minutes. So these guys weren't getting paid. We just took that money, and put it toward the rent, basically. They did it because they were friends, and I had battalions of them. I mean, I had anywhere from three to six roommates at any given time, so it was because of their relationship—
- 3-00:31:52
Lage: Did it work?
- 3-00:31:56
Longmore: Yeah. It did work.
- 3-00:31:56
Lage: Did it just kind of flow, or did they have tasks assigned for certain days?

3-00:32:00

Longmore:

Different guys would work different times of the day, different days. They were all doing the same stuff, though. But they were also doing stuff for the whole household, like, you know, one guy would be assigned to cook dinner on a given night, or do the dishes, or something else. Assisting me, that got divvied up as well.

The first year was really hard because my mother had always assisted me, and now I had to explain to people how to do what. I had to get over my shyness, and my wanting a lot more privacy than was practical for me to have. So I would train people one at a time. I might have a group of roommates, but I would let one of them come and help me, and not have a bunch of them together simultaneously learning how to do these things. And I had to learn how to direct them, how to explain to them. Eventually, when I started using paid assistants, years later, then I had to learn how to hire, and manage, and supervise, and fire. I mean, I had to fire some people. I had to learn to deal with people who were irresponsible, who failed. I mean, I had one guy one day, just starting. I said, "Okay, I'm going to get in the shower, now, and I'll get myself all wet, and then you come and put the shampoo and the soap all over me." And he said, "Okay." And I did that, and then I called him, and there was no answer. So I climbed out of the tub, and looked around the apartment, and he was gone. I think he freaked out, you know, and left. [both laugh] You know, I had other people who really were serious problems to deal with. I had to learn how to manage them. And also, at the same time, I had to learn how to manage money.

3-00:34:12

Lage:

You mentioned that last time. You had none of that experience.

3-00:34:13

Longmore:

Yeah. None of that. I had to teach myself all this stuff that first year or two. And then, you know, when I had groups of roommates, I was the one who took care of the rent; I was the one who paid the bills, and the utility bills.

3-00:34:30

Lage:

So that was kind of your job?

3-00:34:31

Longmore:

Yeah. Well, they were there because of me. It was a household, you know, we had these friendships. But, you know, I was sort of the centerpiece of the household, and so I was the one financially responsible. The leases were always in my name. And some of the roommates I ended up having to deal with. I had one roommate one time, in one house I lived in, we were renting this place and the landlord had somebody patch the cement walk right out front because it was broken. And so this guy decides to put a heart with his initials and his girlfriend's initials in this fresh cement. And I said to him, "We don't live here. This isn't our property." And there were things like that where

I had to deal with people, roommates, who there was like a difficulty with. That was a pretty easy one, but...

3-00:35:39

Lage: Did you feel like you had to be—you talked about the imperative to be cheerful and overcoming. I would think there would be some of that in this independent living setting.

3-00:35:51

Longmore: Well, yeah. One of the things that happened initially was I felt like I had to get along with everybody. I felt like I couldn't alienate anybody, I needed everybody. What if they left?

3-00:36:03

Lage: You had to be the good guy.

3-00:36:06

Longmore: Yeah. And then I got married, and interestingly this coincided with my allowing myself to be more alienated from the church. I realized, because my wife was the one who was assisting me for everything, which was a mistake, definitely.

3-00:36:26

Lage: What year was that?

3-00:36:28

Longmore: I got married in '77. And we were together until eighty-two, or eighty-one.

3-00:36:38

Lage: So she took over the personal assistance.

3-00:36:42

Longmore: Yeah. She did because we didn't have any money. I lost most of my benefits when we got married. They drastically cut them. She had to reduce her income, even, for me to be eligible. And the reason we did that was because I needed the Medi-Cal insurance to pay for my ventilators because we couldn't afford that. So it was a mistake. It was too much for one person. It was also not a good idea for me to have to depend only on her. But the positive thing was I realized there are all kinds of other ways for me to get what I needed. It wasn't just one way.

And we split up, and then I started to hire people for the first time. And I would get, usually, lots of applicants for the jobs. And usually still do. So over the years, I've lost count, but it's got to be over a hundred people who have worked for me. And some of them last a long time. The longest is about seven years. Five years in another case. The shortest is a few weeks. And everything in between. And one of the things I began slowly to realize was there are always going to be ways to solve these problems; there are always going to be ways for me to get what I need.

3-00:38:11

Lage: Maybe different ways at different times.

3-00:38:12

Longmore: Yeah. And it has been. I've had different kinds of people at different times.

3-00:38:15

Lage: Do they usually live in?

3-00:38:17

Longmore: Some do, and some don't. Sometimes I've had college students, predominantly college students. And for a while I was getting a lot of middle-aged divorced women. I've had older people, younger people, everybody in between. All ages, all kinds of backgrounds. And in addition, as I advanced in my career, finally had a career, then I also got more sure of myself, and sure that I had a right to insist on what I wanted. So I say I've become more assertive, and more directive as I've gotten older. Age also makes a difference. I mean, you get to the point where you say, "I'm fifty-five years old. I don't have to put up with this any more." I put up with it when I was twenty-five, but I'm fifty-five now, and I'm damned if I'm going to tolerate being condescended to by somebody I'm paying. And I've had people who have tried to be condescending. So over time, as I interview people, and hired them, and then began to employ them, I developed particular ways of relating to people, so that in the initial interview, I got to the point where I started to say, "This is not a nursing job; I'm not a patient. It's my home, not a hospital. I'm in charge, and we do things the way I want to do them if it matters to me. With a lot of things, a lot of chores, I don't care how you do them, just so you get 'em done, and do them well. But with some things, I'm going to insist on doing it my way, and in that instance, you're my hands." Some people will say, "I don't have any experience with this kind of work." And I usually say, "That's good, because I don't want you to have prior experience. I don't want you to have preconceptions or ideas about how this ought to be."

3-00:40:32

Lage: You don't get former nurses?

3-00:40:34

Longmore: I have very rarely hired former nurses, and when I did, I regretted it. I did interview one nurse one time, since I've lived here in San Francisco, and she went around the apartment with me, I showed her things, I explained them, and she said to me, "Well, I can see there's a lot here that needs to be looked at, that needs to be supervised." And I said, "...No." And she said, "No?" And I said "No." And she said, "Oh. Well, we disagree." And, "Yes, that's right. And that's why you're not going to be working here."

3-00:41:16

Lage: [laughs] You've lived a lot.

3-00:41:18

Longmore:

Yeah. I have. And now I make very clear by not only what I say explicitly, but my whole manner of managing PAs that it's my life, and I'm in control of it. One of the people who lived with me here for a long time really didn't know much about disability before she moved in, but I credit her with really getting what I meant when I said, "It's my life and I'm in charge of it, and you're here to help me with that." Because at various times, friends of hers would ask her questions about me, and I would hear her explain to them that she didn't run my life, that I run my life, and she's here to assist me in the tasks I needed to get done on a daily basis. And in fact, I had a girlfriend at one point who said to her, "You need to make sure that Paul does such-and-such," because she was concerned about my physical health. And my aide said, "Oh, no. I couldn't do that. I couldn't tell him what to do. He wouldn't listen to me." So I guess I've become more assertive as time has gone on.

3-00:42:42

Lage:

With age as well as ideology.

3-00:42:44

Longmore:

Yeah. Age makes a big difference. It really does.

3-00:42:47

Lage:

Let's see. I had one more follow-up. We're not moving forward too far, but we're picking up a lot of areas. We talked about this ideology of overcoming, and it sounded from the way you talked that it was just kind of in the air. You didn't really tell me whether you were told that—you, yourself, specifically—or was FDR held up as a model to you, or was it just in the culture out there.

3-00:43:17

Longmore:

Well, it is very explicit. There are all kinds of messages people with disabilities get about overcoming.

3-00:43:28

Lage:

Right. Do you remember something that came to you?

3-00:43:31

Longmore:

Well, the specific location of it is in rehabilitation, or special education. And implicitly, if not explicitly, when somebody tells you, "You need to learn how to dress yourself. You need to learn how to feed yourself. You need to walk rather than riding in a wheelchair," which I did for a long time, which was okay for me for a long time, but other people I knew should have been using wheelchairs when they were walking, wearing leg braces and using crutches, and they really wore their bodies out. All those imperatives are there explicitly in rehabilitation, and when you get labeled as "maladjusted," or "resistant," or "uncooperative," or "recalcitrant," the message is pretty clear as to what you're supposed to do. Then the more general conveyance of these same messages, this same ideology, is in popular culture, especially. So you see, on television let's say, you get non-fictional stories a lot about somebody with a disability doing some physical stunt, you know, like the fellow who climbed

El Capitan a number of years ago. TV has been filled for years and years with those kinds of stories. And the explicit message is often, the person is asked, “Well, what do you want to tell other people with disabilities, and the rest of the world?” “You can do anything you set your mind to do.”

3-00:45:22

Lage: Yeah. I see what you mean. It’s just so widespread.

3-00:45:25

Longmore: Right. And then you get fictional stories in which what you have is a bitter, maladjusted, self-pitying person with a disability. And the problem there is they’re not coping; they’re not striving; they’re not overcoming. So it’s there all the time. And then you get it from acquaintances, and perfect strangers, or you might even get it from your own family. So you complain a little bit about something, and suddenly you’re regarded as bitter and self-pitying. “Now, don’t feel sorry for yourself.”

3-00:45:59

Lage: And do you remember getting those messages?

3-00:46:02

Longmore: Oh, yeah. I’ve gotten that at times, and I usually slam the person who says that. And then, of course, that just proves how bitter I am. You know, “You got to have a positive attitude,” you’re told.

3-00:46:23

Lage: It’s also a very American attitude.

3-00:46:25

Longmore: Yes. All of it is deeply rooted in both modern, and particularly American, cultural values. Because the modern notion is that human beings are in control of their own fate. And that is especially true of Americans. It’s no accident that, reportedly, FDR’s favorite poem was a poem that school kids, especially boys, were drilled in memorizing. *Invictus* by William Ernest Henley,

OUT of the night that covers me,

Black as the Pit from pole to pole,

I thank whatever gods may be

For my unconquerable soul.

In the fell clutch of circumstance

I have not winced nor cried aloud.

Under the bludgeonings of chance

My head is bloody, but unbowed.

It matters not how strait the gate,

How charged with punishments the scroll,

Now here's the key:

I am the master of my fate:

I am the captain of my soul.

Now, that predates rehabilitation, but it's there. It's there in the ideology of rehabilitation. And a lot of people, like FDR, bought into it. FDR did not need professional rehab doctors, or physical therapists, or occupational therapists at Warm Springs to establish this ideology. He bought into it.

Now, in one sense, it's really a logical strategy, and maybe a necessary one, at that historical moment because the perception of people with disabilities, physical disabilities anyway, was cripples: helpless, dependent, unproductive, marginalized, really outside of society or at the edge of it. And what does FDR want? He wants to create a different kind of persona in which physically disabled people can participate in community life. And he can get back into politics, and get elected governor and president. And a lot of other people who had polio at Warm Springs, it's clear, had the same idea. They wanted to refute that image of the cripple. So what do you establish as the alternative, as the counter-image? They created the overcomer. It's only a later generation, I think, two generations later, building on that, that moves them from being overcomers to being disabled persons who are political activists.

3-00:48:58

Lage:

But there's some overcomer mentality in that as well.

3-00:49:00

Longmore:

Well, there is. I mean, I've said often that I think a lot of political activists are overcomers who shifted overcoming from the personal to the political, and basically used all that striving to try to reform society, but still work our heads off, maybe to the point of exhaustion, or, you know, a kind of physical detriment. But I think the first generation of activists were people who had been told in rehabilitation, "You can do anything you want if you set your mind to it, and the only obstacle is your own will; your own willingness to transcend your limitations and make something of yourself." And that was especially true of people who had polio.

Well, what happened was a lot of us who came of age in the 1960s had these aspirations, strove, and then hit a kind of glass ceiling, and realized that there were other obstacles that were external to us: inaccessibility, discrimination, institutionalized policies that restricted us. And we're simultaneously influenced by the civil rights movement and the women's movement, and we start to apply those ideas, those principles to ourselves, to our own situation. I can remember when I first got involved in the L.A. disability rights movement, around 1980, a little bit after that I had dinner with a friend one day, who was not disabled. And I had already thought about prejudice and discrimination for a long time, but I was thinking about it now at a new and deeper level, and because I was in touch with other people with disabilities, particularly activists, I was really getting in touch with the pervasiveness of prejudice and discrimination. And I said to him, "Look, if what I was taught growing up is true, that this is just a matter of me coping, I can do that. I know I can do that. I've done it. But if it's a matter of 'we're a minority group' and there really is social oppression, then it's not going to be solved in my lifetime. It's not going to be solved in several lifetimes, and I'm not sure I can deal with that. I'm not sure I want to face that." But that, in fact, is what I ended up doing, and what we've all ended up doing. We did have to come to grips with that reality.

3-00:51:49

Lage:

There are kind of two directions we could go in, as far as I see it. We can continue with the story of your involvement with the disability rights movement in L.A. and the changes there, or we can go back and talk more about your intellectual development.

3-00:52:04

Longmore:

Whichever you prefer, it's fine with me.

3-00:52:06

Lage:

—and becoming a historian. I mean, they're kind of happening together. I guess I would go back and do the historian story, and then it all seems to come together in the last phase of your...

3-00:52:30

Longmore:

History. I got interested in history starting at about the age of nine. And I first read juvenile historical fiction, which I'm sure I would be appalled at if I re-read it now.

3-00:52:44

Lage:

Do you remember the type of things?

3-00:52:46

Longmore:

There were series of historical fictional novels for boys, for kids my age, nine, ten, called *We Were There*. It was all series. *We Were There At the Boston Tea Party* [by Robert N. Webb], things like that. And then, when I was just a little bit older, ten, eleven, twelve, I read the *Landmark Books* that Random House

published. And there were, at the time, about a hundred and thirty of those books. I read all of them. And I'm sure that now I would be really appalled.

3-00:53:24

Lage: Were they basically American history?

3-00:53:26

Longmore: American and world history. I would go to the library and get four of them out at a time, and I would read them all over a period of two weeks, and then go get another four. And then, in junior high and high school, I got more into history, and especially Early American history. And then went to college and I majored in political science because at that point I thought I was going to be a lawyer. So I was taking more history classes than Poli Sci classes, and one of my history professors said to me, "You know, you're taking more history than anything else. Why aren't you majoring in history?" I said, "Well, I'm going to go to law school." And he said, "Well, you can go to law school and major in history." And I said, "Oh. Okay."

3-00:54:16

Lage: Was this Santa Clara?

3-00:54:16

Longmore: Yeah, Santa Clara.

And we started a chapter of Phi Alpha Theta, the national History Honors Society. I was its first vice president. I transferred to Occidental and became the president of the chapter of Phi Alpha Theta there. So I got really involved in—

3-00:54:38

Lage: Do you know what attracted you to history from such an early age?

3-00:54:41

Longmore: Well, not only was I interested in history, but I was really interested in the period I've always studied: the late colonial period in American history, the period leading up to the Revolution. All my published work in early American history has been in that period. My book on George Washington, the journal articles I've published, have all been located in the half-century, or seventy-five years leading up to the revolution. I think there are a couple things about it that have always intrigued me, and I didn't realize this for a long time. What happens in that moment and just after the beginning of the revolution is a transformation of people's values and identities. They start out defining themselves as monarchists, then they become republicans. They're British, they become Americans. Not everybody, but substantial numbers of people. It's not individual—well, it is, but it's individuals who are involved in a collective transformation. So the individual transformations are never experienced alone; it's always in that context of what's going on in the society at large. A lot of this is about the emergence, in this moment, of distinctively

American patterns of politics, and religion, and social relations, and gender relations, and particularly nationalism.

One of the projects that I'm working on now, and I've been working on for the last few years, has to do with nationalism and the coming of the American Revolution. And I've never been satisfied with the answers that early Americanists have given about that. So I'm trying to compare that nationalism with other nationalisms in other parts of the world, in other eras. A lot of historians don't think there was American nationalism at that point. I do. I think that probably part of the appeal to me was these are conversion experiences, and that's the culture I grew up in, that evangelical culture. There's a Greek word in the New Testament, *metanoia*, a transformation of mind. It's really a transformation of who you are, and what you are, and how you view things, how you understand things, how you understand the world and your part in it. It's a total transformation. And that's the description of what happens. Salvation is not simply your soul is going to go to heaven, it's much more than that. It's subsequent to that, God transforms you into someone else. That's the objective and ideal. So there's a kind of *metanoia* in a way that goes on with these American Revolutionaries.

3-00:58:20

Lage: And you think that's what caught your imagination?

3-00:58:22

Longmore: Well, I'm interested in how people go through these kinds of conversions. What brings it about? What does it entail? What's it feel like?

So my book on George Washington is really about that on one level. The most important and interesting passage to me is when I talk about in one chapter about the overthrow of King George III, and the replacement of him with George Washington. The overthrow of monarchy, and the substitution of Republicanism, and what a traumatic transformation this was for a great many Americans.

[Audiofile 4]

4-00:00:00

Lage: Okay. We are continuing with tape 4.

4-00:00:04

Longmore: Wow. What a yakker.

[both laugh]

4-00:00:07

Lage: We've always known that.

4-00:00:09

Longmore: Yes, we did.

I didn't get into disability history until after I had finished graduate school. In 1983 I met Harlan Hahn, a political science professor at the University of Southern California. And he told me he was going to teach a summer school class on disability studies—well, we didn't call it "disability studies" then, it was disability and society—and invited me to sit in on the class. And the result was the class became virtually a conversation between Harlan and me in front of the students, and at the end of the course, Harlan said, "You know, my dean's offered me a small budget to explore setting up some kind of program, and there's money enough to hire somebody part-time to be the administrative person for this." So I said, you know, I don't have any prospects of a job, I was finishing my dissertation at the time, so I said, "Yeah. I'll take the job."

So I went to USC, and the first year I just was a salesman who went around, and I think I talked to something like eighty-five faculty and administrators in every part of the university, and said, "What we're trying to do is create a curriculum that will look at disability as a social and political issue, and not a medical issue; a minority group status, rather than a medical status." And some were interested, and some weren't. Anyway, in the course of doing that, I started to think for the first time about the history of disability. And hardly anything had been done in that area, and certainly nothing from our perspective, from this minority group perspective. So I thought, "Well, I'm trained as a historian, maybe I ought to apply my skills to beginning to look at disability history." Not coincidentally, the people who became the first practitioners of what we would in a few years from then call disability studies in the U.S. were all, pretty much all of us, were academics trained in various disciplines who had trained to do other things. I mean, Harlan made his reputation working on Black politics, and doing other things, and there were other people like that. Irv Zola, Irving Zola, was a sociologist who had made his name as a medical sociologist and he started to look at disability.

4-00:03:11

Lage: And was he a person with a disability?

4-00:03:13

Longmore: Yeah. All three of us had polio. So it was kind of characteristic of what would become disability studies in that era.

4-00:03:22

Lage: I want to go just a little bit more back into the history. Just becoming a historian, were there professors who were particularly important? I mean, is that an important story, your studies at Claremont Graduate School?

4-00:03:38

Longmore: Well, yeah. Okay. You read the essay I wrote on *Why I Burned My Book*,¹ in which I talk about professors who encouraged me, and professors who discouraged me. That was as an undergraduate student and an MA student at Occidental College, and then at Claremont Graduate School, there were some who were really supportive, who believed in me, who believed I could do this work and become a university or college history professor, and there were others who said, “No one will ever hire you.” And some of them actively discriminated against me.

4-00:04:13

Lage: But how did they treat you, just as a person becoming a historian? Was it ever able to be divided out?

4-00:04:20

Longmore: Well, the one overt negative thing was I was denied a fellowship my first year on my PhD. I tried to get other kinds of financial aid from various sources, though I got turned down. I got turned down by the Department of Rehabilitation the first time I went to them, and they said, “We don’t help people get PhDs.” And later on I found out that that wasn’t true. They could. I just had to be insistent about it, and not take “no” for an answer.

4-00:04:53

Lage: And then the fellowship just sounds a lot like what women used to face: “Oh, you’ll just get married.”

4-00:04:59

Longmore: Oh, yeah. It’s the same thing. This is an era in which there were very few women in the PhD program. Not many at all. Now it’s more than 50 percent in PhD programs in history and other fields. Back then there were only a handful of women, and I can remember in one class I took my first year of my PhD, I thought the smartest person in the class, including the professor, was one of the women students. And yet, she would speak up and the professor, who was male, and the other male students would kind of dismiss what she had to say. I found that kind of surprising.

4-00:05:44

Lage: How about yourself? Did they take your own statements seriously?

4-00:05:49

Longmore: Well, you know, I think I mentioned before that one of the things I had decided early in adolescence was I needed to take control of perceptions of me

¹ Paul K. Longmore, *Why I Burned My Book and Other Essays on Disability* [Temple University Press, 2003].

when people first met me. So by the time I got to graduate school, I had developed this manner, this style of presenting myself that represented me as very smart, very articulate, very strong, don't mess with me.

4-00:06:17

Lage: Just what you need in a seminar.

4-00:06:19

Longmore: Yeah. Exactly. I was also, though, shy. That's what they didn't know. I was pretty timid. So, I would sit in these graduate seminars in my PhD program, and I couldn't raise my hand—this would have been true as an undergraduate as well—I couldn't raise my hand to get called on. So I would just have to interject myself, just speak up. And that was a lot for me to do. And there were lots of times when I didn't speak up when I had something to say, and I would miss opportunities, and I would really berate myself, especially if somebody else would eventually express the idea that had been in my mind. So nobody else was aware of what was going on. I was really fretting in those classes about this. In fact, there were enough times when I did speak up that I think the effect was probably stronger on how they perceived me than if I had spoken up more often, because those moments when I spoke up were, I guess, inadvertently, unintentionally on my part, really well-chosen strategic moments. I mean, it would be something important—a moment, I mean—in the class discussion. And I would have carefully thought through exactly what I wanted to say because I'd have been kind of rehearsing it in my head because I was so scared, and then I would deliver myself of these observations. I think the result was they thought I was a lot smarter than I was. And I remember one day talking to a fellow student out at Claremont, and he made some remark about how smart they all thought I was, and I thought, “Well, that's odd.”

4-00:08:22

Lage: You didn't disabuse him of that notion?

4-00:08:23

Longmore: I can remember I was smart enough to keep my mouth shut at that point.

4-00:08:28

Lage: Well, do you think your professors had similar views?

4-00:08:30

Longmore: I think they thought I was pretty good. Although at that point, early on I don't think I was working up to my ability. I wasn't certainly getting as much out of the studies as I could have. And there came a time point, it was in 1975, I was four years into my PhD, and I had had very little money, I think I mentioned this last time, L.A. county established this financial aid just for people who had polio and used respirators and lived in the county to hire more personal assistants. Everybody else used it to increase the pay of their in-home aides. I used it to hire a transcriptionist.

That coincided with something else that happened. I was going to turn twenty-nine in July. In January of that year, I took a directed readings course with one of my professors, and the subject was foreign travelers' views of America from the colonial era on up to the twentieth century. And at the time I thought this might be a dissertation topic. So I read that stuff and I read some theoretical literature on culture and society and national character, and all that stuff, which was still big in this era, it's kind of passé now. And I had to write an essay for this professor. It didn't have to be a long one. It was, I think, fifteen pages. And I said to myself, this is now about March of that year because I had already starting in January started to think, "You're going to be twenty-nine in July. What have you *done* with your life? You haven't gotten anywhere. You know, you really haven't made much progress, you're still taking coursework, you haven't finished your coursework, you're not onto the dissertation, you haven't passed your qualifying exams. What are you *doing*?"

So I had to write this essay for this professor, and I said to myself, "You know, you have never written anything that you thought was the best you could do. You have never really worked up to your ability. With this essay, write it, and re-write it until it's the best you think you can do, and then turn it in." So I spent a whole month working on one fifteen-page essay. And when I turned it in, I thought it was the best I could do. Not the best I ever would be able to do, but the best I could do at that point in my life, in my intellectual development. And that was a turning point—I mean, getting the money that I got then to hire a transcriptionist, and making that decision. From then on, I started to work a lot harder.

4-00:11:34

Lage:

And how was the reaction to your—?

4-00:11:37

Longmore:

He thought it was good. Years went by and I would think about that essay, and I would think, "Well, he thought it was good at the time. I wonder what you'd think of it now." And finally in the summer of 1990 I was getting ready to leave L.A. to move up to Stanford, and I went through all my papers to see what I was going to keep and what I was going to toss, and came across that essay. And I said, "Oh, I haven't read that in fifteen years." So I read it. And I thought, "Wow. This isn't so bad. I think it's pretty good." But the most important thing was it was a turning point, and after that I really started to work harder, and I really started to blossom, and really started to develop as a historian, as a scholar, as an intellectual.

4-00:12:27

Lage:

And did this lead to new ways of thinking that you might have applied later, or is that something that you can put into words?

4-00:12:37

Longmore:

I'm not sure. Do you have something in mind?

4-00:12:40

Lage: No. I don't. But it seems to me that part of the education is a method, or a discipline, or a deal-with-the-world almost.

4-00:12:49

Longmore: Well, it was certainly a matter of discipline, a matter of application. Yeah. Because one of the things I struggled with, and still struggle with, is procrastination and feeling overwhelmed by all the work and how hard the work is, or how hard I think I need to work, or what the quality needs to be. And when I was younger I could have done a lot better as a student. I had an incredibly good memory. I mean, it was easy for me to learn stuff. And I took pretty good notes in classes. So if I would go over my notes in preparation for an exam, just reading the notes three times, I would virtually have my notes memorized. But I would read through them the first time, I'd start through the second time, and halfway through I'd say, "Oh, this is so tedious, I can't take this," and I'd stop. So I'd ended up getting Bs when I could have gotten As. And after this moment in early '75, that started to change. I started to apply myself more and be more disciplined and work a lot harder.

4-00:14:19

Lage: I want just to clarify the transcriptionist. Did you dictate your paper?

4-00:14:24

Longmore: I had a Dictaphone, I still have a Dictaphone, I would dictate on audiocassettes, give the tape to the transcriptionist, they would have their own transcription machine, well I mean, you know all of this stuff, and then they would give me back the typed notes. And a lot later than I should have made the transition, I finally switched from typed notes on paper to transcription onto diskettes. And now what I do is I get transcribed files as email attachments from my transcriptionist.

4-00:15:02

Lage: But when you're writing a paper, are you dictating it?

4-00:15:04

Longmore: I used to. For a while I dictated. Well, I originally had typed on a typewriter. I got my first electric typewriter when I was in junior high, and I typed my stuff mostly. And then typing it just got too hard physically, writing got too hard physically. I stopped doing all that. So I had to start dictating. And it ruined my prose style.

4-00:15:32

Lage: It's a learned thing to be able to dictate like that.

4-00:15:34

Longmore: Well you can't see any of it. It's all on audiotape, and you can't go back and correct it. So my writing style which had been pretty lean and economical became very convoluted. And it would be a couple weeks sometimes before I got the transcriptions of what I dictated. So it was a really bad way to write. And then, finally, I started to type on a keyboard on a computer, and I did that

for a long time, for years, and then I started to use Dragon NaturallySpeaking which is mostly what I dictate with.

4-00:16:13

Lage: And then you can go right back and correct and edit yourself?

4-00:16:17

Longmore: Well, the problem I have is that with the ventilator mouthpiece, there's a lot of noise that interferes with Dragon. And it makes a lot of mistakes. But it's necessary physically for me to do it that way. So I mostly use Dragon. I also use an on-screen keyboard that I operate with a mouse, although that's a little too physical as well. I don't dictate notes that way. I just write that way. And personally when I'm writing now I do it that way so I can see it immediately and make changes. And after I switched back to doing my own direct writing, my prose style changed again. I became, again, leaner and more economical than I had been for a while.

4-00:17:08

Lage: Now, how are you doing, tiredness-wise?

4-00:17:09

Longmore: I'm fine.

4-00:17:14

Lage: Should we go back and pick up the involvement with the disability rights people in L.A? Or where do you think we should go?

4-00:17:20

Longmore: Let me continue with this thing about getting into disability history because it is actually connected. Once I got into disability history—well, the first things I did were, one of my dissertation advisors at Claremont was on the editorial board of a journal called *Reviews in American History*. It's a major journal in the field. They're essay-length book reviews in which you don't just review the book, you review the historiography on that subject. He was on the board; the editor said to him, somehow, "I'm looking for somebody to review two new books on George Washington." And he said, "I've got a student of mine who you ought to ask to do it." So I got that chance, and the editor really liked what I wrote. He said, "If anything else interests you in the future, let me know."

So I said, "Well, there's this new book, a biography, coming out on Randolph Bourne. It's just come out, and I'd like to review it in the context not just of studies of Randolph Bourne, but studies of the history of disability." So he said, "Yeah. Go ahead. Do it." So I read everything about Bourne I could read in three months, and I had first encountered Bourne—I mean, I have that essay in the book, *Why I Burned My Book*, it's the review essay I wrote for him. I had encountered Bourne back in the late sixties because antiwar activists read Randolph Bourne's antiwar writings from World War I. I read

that, but I went on and read other stuff, because what they didn't pay attention to was that Randolph Bourne was physically disabled.

4-00:19:11

Lage: Nobody—

4-00:19:13

Longmore: Nobody paid attention to that, really. And he wrote about it, too. So I read all this stuff, and incorporated that into my review. And then the editor really liked that one. He said it was a pioneering article, because I called on historians to look at disability history not from a medical standpoint, but from a social, cultural, and political standpoint. And then he said, "Well, anything else you want to write?" And I said, "Well, there are these three other books on disability history. I'd like to do another essay on them." So he said, "Okay," so I did that one, too. And that was a kind of overview of modern disability history.

Anyway, I took the reading that I had done, and I developed a public lecture. This is in the mid-eighties that I wrote these things. I developed a public lecture on disability history. Now here's the connection with the other historical stuff. In 1988, my book on George Washington, what had been my dissertation, was about to come out. I was invited to come up to speak in the Bay Area on various campuses. One of them was UC Berkeley.

4-00:20:30

Lage: Around the book on George Washington?

4-00:20:32

Longmore: No, no, on disability stuff. And the lecture I gave eight times in one week was on the history of disability. I went to Berkeley to talk to a group of disabled students there. Well, UC Press published my book on Washington, so my copy editor came to hear me talk. And I talked about the history of people with disabilities, and changing values, and changing identities, and movements, and the radical transformation that was taking place. And she came up to me, the copy editor came up to me afterwards, and she said, "What you're talking about is the same thing as what you're talking about in your book on George Washington." And I said, "Yeah, I know."

I had finished the dissertation and hadn't realized that. Everything I end up working on has to do with social identities, and how they get defined; that is, the social identities of individuals and groups. How social and cultural, and even political values shape those identities; how people get control over the definitions of their identities and of their social careers; and transforming historical moments when, particularly, groups of people come together to try to change those definitions and those possibilities. It's there in the George Washington book; it's there in virtually everything written in disability; it's also there in the other stuff I've written in early American history.

4-00:22:23

Lage: How do you explain it?

4-00:22:27

Longmore: I don't know.

4-00:22:26

Lage: Were you thinking of disability parallels while you were writing the George Washington book?

4-00:22:31

Longmore: No. I didn't even pick the George Washington topic. One of my professors at Claremont said, "You've got to do a seminar paper for me." It was a course on early American history. He said, "You have to do a seminar paper. The history of the image of George Washington has never been written. It would make a great dissertation topic. Would you like to do your paper on that and explore the topic as a possibility for a dissertation?" So I said, "Okay." So I did the paper, and I said to him, "Yeah. I think I'd like to do a dissertation on this." I didn't pick the topic.

4-00:23:08

Lage: But you liked it.

4-00:23:13

Longmore: I liked it. It was interesting. It was an important topic.

4-00:23:14

Lage: But you were not connecting it to self.

4-00:23:16

Longmore: So then I got into it, and the idea was to do the history of his image, and as I got into I thought, "Well, you know, during his lifetime his images were all wrapped up with his biography, with what he actually did. And he's a part of the creation of his image, and he's responding to how people perceive him. He is responding to the same cultural and ideological influences that are shaping how they've perceived him. They all share these values. They think, 'This is what I ought to be as a leader.'" So he's trying to live up to those things. He's also trying to redefine himself as they are trying to redefine themselves. So it ended up being as much about his early career as about his image, and its origins, its genesis. But I didn't think about disability at all.

But there were a whole set of issues there that were issues that I had personally grappled with and would continue to deal with, and then just when it was even doing disability studies, or disability history, or disability activism. I mean, that came later. But it's still the same issues.

4-00:24:30

Lage: But could it be that you sort of got very involved in analyzing these issues, and then that's one reason why you chose to think about those issues in disability history?

4-00:24:43

Longmore: Well, I think maybe it was because of what I was dealing with in all these other areas of my life, I was able to see things in his life, and his career, and his historical context that other historians, his biographers, had missed.

4-00:25:02

Lage: I see. Is this why you feel that disability is a good way to look at history, one way to enter it?

4-00:25:10

Longmore: Well, I'm not sure that I would say that disability provides a lens to look at George Washington, or that historical moment, but it certainly does provide valuable ways to think about all kinds of other history, because it's really there quite explicitly. One of the first essays I published on disability history I got a note from a historian who does sports history. Now, I'm not sure what he meant exactly, but he said, you know he's writing about the history of baseball in the late nineteenth century, and, you know, "What I read in your essay helps me think about it in a new way." I'm not sure how, but maybe it had to do with disability indirectly, maybe not at all. It's just another angle.

4-00:26:01

Lage: A new way of seeing things.

4-00:26:09

Longmore: I don't know. Maybe it's the phases of the moon.

4-00:26:14

Lage: Maybe it's the outsider perspective.

4-00:26:14

Longmore: Well, I think that's very much what it is. Although George Washington is anything but an outsider.

4-00:26:21

Lage: Right. He wasn't an outsider.

4-00:26:20

Longmore: Well, yes he is, and he isn't. I mean, he becomes an outsider. He's a guy who thinks you have to be an insider, and he becomes a revolutionary because they make him an outsider. He and a lot of other British colonials in North America don't get what they think they're entitled to as members of the British colonial elites.

4-00:26:44

Lage: Yeah. They're outside the British hierarchy.

4-00:26:46

Longmore: Right. And they think they ought to be inside, and what they're expecting in this historical moment is, which is overwhelming triumph in the Seven Years' War, "We will now be incorporated into the imperial ruling class." And instead what they gradually discover is that there's a program afoot to revamp

the administration of the empire and reduce the power of colonial political leaders through the legislatures to impose stricter imperial control over them, and that's what really sets off people like Washington. He's among the first to be outraged by this and to want to rebel against it. And he's, in fact, in a certain way one of the most radical. He is the leading nationalist in that moment. One of the first. And a lot of other people share those feelings sooner or later and follow after his lead. So he's an insider, or a would-be insider who is forced to the outside, and I feel like I can identify with that in a way.

I have a friend, that psychologist I mentioned the last time, a disabled person. At one point in our conversations she said to me, "You know, in a way, you're kind of hyper-male." And I said, "Well, how's that?" Because I like to think of myself as some kind of feminist. [Lage laughs] But anyway, she said, "Well, if it weren't for polio and disability, as a white male with the kind of education you've had, you would have had all the opportunities that are just the epitome for people, white males in particular, in this culture. And the only thing that's prevented you from enjoying all those privileges and advantages is that you became disabled, and very disabled. And I think you're really outraged by that. You feel a sense of entitlement that's been denied you, and the result is you've become so militant politically about disability rights."

4-00:29:12

Lage: How did that strike you?

4-00:29:14

Longmore: I thought it made a lot of sense. I mean I think that accounts for an awful lot. So I may be that. It's interesting. She was on a panel on disability issues at L.A. City College, at some conference that we had during the eighties, and there was another psychologist on the same panel with her, and he heard me speak on the preceding panel, and he found my activist militancy kind of disturbing. And I don't know if he said it on that panel, or if he said it to her privately, but he said to her that it was clear I was maladjusted. [both laugh] And she told me this, and I said to her, "Well, tell him that George Washington was maladjusted." Oh, wait. I know what he said. He said, "It's clear that Longmore has problems with dealing with authority." [Lage laughs] That's what he said. He didn't say I was maladjusted. But that's the implication. "It's clear that Longmore has problems dealing with authority." And I said to her, "Well, you tell him that George Washington had even bigger problems dealing with authority. If he hadn't that guy would be speaking with a British accent." [both laugh]

4-00:30:29

Lage: Well, there's humor in all of it, too.

4-00:30:32

Longmore: Oh, yeah. I think disability is really funny.

4-00:30:36

Lage: [Lage laughs] That's great. Well, maybe we should stop for the day.

[Lage and Longmore discuss ending the interview.]

4-00:30:52

Longmore: Well, there's a lot more to say about disability studies, of course, and disability history, but that will come later.

4-00:30:59

Lage: And also, I want to get more about your involvement with the disability rights, the early involvement in the early eighties. And then more about the USC experience, because that seems like a really important time. Is that right?

4-00:31:14

Longmore: Yeah.

4-00:31:16

Lage: And then what's next after that, do you think?

4-00:31:21

Longmore: Well, in terms of my autobiography, there's everything that happened in the nineties and since.

4-00:31:25

Lage: But, I mean what's the next logical thing?

4-00:31:29

Longmore: Well, how did I suddenly have a career?

4-00:31:34

Lage: Okay. That's good. But let's go back sort of to where we had left off last time and pick up that thread. Sound good?

4-00:31:44

Longmore: Yeah.

[Interview 3: October 11, 2006]
[Audiofile 5]

05-00:00:00

Lage: Today is October 11, 2006. I'm back with Paul Longmore for our third session and everything seems to be recording fine, so let's go forth.

05-00:00:27

Longmore: Okay.

05-00:00:28

Lage: We were going to start today to get to that subject that we kept referring to but had not gotten into, that is, how you got involved with the disability rights movement in L.A. and what that meant for you.

05-00:00:41

Longmore: Well, the first involvement I had, I think I talked about this a little bit before was, in the late seventies. The L.A. County Board of Supervisors created a post-polio supplement, they called it, with financial aid to residents in the county who had had polio and used respirators. There were about ninety of us at the time, and the county knew that we'd cost a lot more if we couldn't stay in our own homes, because the only place to go was Rancho Los Amigos Rehabilitation Center and the cost for people to live there would have been exorbitant. Anyway, as a result of the creation of this post-polio supplement, the Polio Survivors Association formed in L.A. County. It was just in the county, it was people who were getting the supplement and for a time in the late seventies, I was on the board of that and then—

05-00:01:56

Lage: But you had said that organization didn't really have a rights orientation.

05-00:02:02

Longmore: It was just trying to deal with the county about maintaining this fund because the board of supervisors had to renew it every so often, but that, for me, was an opportunity to get involved in advocacy and also to get to know other people with disabilities. I really hadn't had much contact, over a long period of time, I mean since I'd been a kid in the hospital. There were several students in college, at Occidental College, three others, two of whom had had polio, but I didn't really hang out with them, and I in fact avoided them, and I think they avoided me.

05-00:02:44

Lage: And was this a conscious thing on your part? Avoiding them?

05-00:02:47

Longmore: Conscious, semi-conscious, I was trying to pass, you know. At the same time, though, I was grappling with issues of prejudice and discrimination and starting to think about people with disabilities as a minority group and disability as a civil rights issue, but the only people around I could have talked to were these three, and I didn't. Strangely I started talking to other people,

friends of mine who were not disabled, so it wasn't until ten years later, in the late seventies that I started to get to know very many people with—well, actually even before that I had mentioned Mary Helen Fisk and other people in the early seventies when I was first struggling to figure out how to live on my own, and they were really helpful. So that's when I really got to know people, and then I got into advocacy with the Polio Survivors Association. Then around 1980, I guess it was, I had made very slow progress on my PhD. I was by then nine years into it, and I was really struggling about money. Well, I guess that's another story I haven't talked about.

05-00:04:22

Lage: Right.

05-00:04:24

Longmore: In 1971, after a year out of school, I applied to Claremont Graduate School, to the History Department, and got accepted and applied for various kinds of financial aid and got nothing from anybody. The Department of Rehabilitation turned me down. They said, "We don't fund people to get PhDs." Other sources turned me down, and so I really struggled. Well, I met a benefactor who gave me the money for the first year, the tuition, and after that first year he didn't provide that aid, and I struggled on. I—

05-00:05:08

Lage: Was he a family friend or—?

05-00:05:09

Longmore: No, it was just a guy I met. I told him my situation, and he thought about it and he called me up and said he wanted to help me, and so he paid my tuition that first year.

05-00:05:22

Lage: It was a private school. It wasn't cheap.

05-00:05:27

Longmore: No, it was much more expensive. One course at Claremont was the equivalent of a full-time load at UCLA, which was one of the things that the Department of Rehab said to me, "You could go to a public university and it would be less expensive." And I said, "I'm at one of the best graduate history programs in the country, and don't I have a right to get the best education I can get?" Anyway, after that first year, I was saving money out of my SSI, Supplemental Security Income, monthly check and accumulating enough in one year to pay for one course per semester, and I did that for a long time. I was getting initially \$135 a month on SSI—did I talk about this before?

05-00:06:33

Lage: You didn't, no.

05-00:06:35

Longmore: I was getting \$135 a month SSI and over five years it increased up to \$185 a month, and I was on food stamps. My in-home support services to pay for people to assist me was \$55 a month; that's all it was.

05-00:06:58

Lage: Heavens!

05-00:06:59

Longmore: I look back and I don't know how I made it, let alone saving enough to pay for—

05-00:07:07

Lage: I mean we've had a lot of inflation since then, but—

05-00:07:09

Longmore: Yeah.

05-00:07:10

Lage: This is still astoundingly—

05-00:07:12

Longmore: Well, I mean I could have scraped by just to live, but not to be able to pay for school at all. And so I had to get a waiver in terms of what's called the residency requirement—that you're supposed to take all your courses in the first two years of your PhD. I had to get that waived, so I went for almost a decade, just taking the courses before I ever got to the dissertation.

05-00:07:39

Lage: And that was a case more of not being able to afford the tuition than how much [coursework] you could handle?

05-00:07:46

Longmore: Oh, no, it had nothing to do with how much I could handle, because I went full-time the first year. No, it had to do with money. It was all money, it was strictly money. Also—well, I said this in the essay on why I burned my book—every semester I thought, “Why am I doing this? I'm never going to be able to get a job because I'll lose eligibility for the medical insurance I get through Medi-Cal, and I'll lose eligibility because of that for In-Home Support Services, and I won't be able to earn enough to replace all that, maybe eventually, after a couple of decades of teaching I can earn enough, but how do I make the transition?” So I thought, “What in the—why am I doing this?”

What really kept me going was I remembered that man that gave me the money the first year. This was a part of my religious faith, and even though I have moved away from that, I still look back at the moment I met him as a providential event. Because I had been praying that if I was supposed to go to graduate school and get a PhD and become a college history teacher that I

would get the money to pay for it. I mean, how I could do it if I didn't get the money and at that moment, I met him.

05-00:09:18

Lage: Just by chance?

05-00:09:20

Longmore: I was at a conference for Presbyterian college students that members of the college fellowship at our church—I was by now a Presbyterian as opposed to a Baptist. It was up in the San Bernardino Mountains, and it was at that conference I decided—well, what happened was I called back to my parents' house and said, "Did the letter come from Claremont announcing whether or not I'm accepted?" And my mother opened it and said, "Yes, you're accepted but they're not giving you any money. And they want an answer by next week as to whether or not you're coming." So I said, "Well, just check off the box and say I'm coming, I'll figure out the money later." So then I sat down in the cabin and I thought, "Well, I've got to decide," and I prayed about it and I decided this is what God wants me to do. And then, of course, I told everybody [chuckling] that God was going to give me the money [laughter].

Three days later, on Saturday, the conference ended, and I was staying around the auditorium where the plenary sessions were held so I could thank one of the speakers. And I came back to the cabin where people from our church were and everybody was gone! One car thought I was riding in another car, and people in the other car thought I was riding in the first car, and they had left. They had headed back for L.A., and I'm stranded in the San Bernardino Mountains. And I mean this was the last conference of the summer, and the people there had just evaporated; they'd just disappeared! So I went around and I said to people there, "I'm stuck here! I need to get back to L.A."

So this young woman had worked there on the staff all summer, and she said, "Well, my parents just came to pick me up and we live in L.A., just west of where you live, so maybe we can give you a ride." So she talked to her dad, and he said, "Yeah, sure, of course." So we're riding down the mountain and I'm sitting in the front seat next to him, and he asked me about myself, and I said, "Well, I got my master's in history and I've been out for a year and now I'm ready to go back for my PhD, and here's my situation." So that was a Saturday. On Monday he called me up, and he said, "I talked to my mother about you." Their family owned a chain of cafeterias in L.A. that I had eaten in as a kid—Clifton's Cafeterias.

05-00:12:08

Lage: Oh! Oh, I remember Clifton's, yeah.

05-00:12:11

Longmore: Yeah. Well, you remember the one downtown with the tropical neon décor?

05-00:12:18

Lage: No. [laughing]

05-00:12:18

Longmore: Neon palm trees. His father was a philanthropist. His father, during the Depression, had offered free meals to people on the street who were out of work who were going hungry, so they had a family tradition. So he calls me up on Monday, he says, "I talked to my mother about you and we prayed about it. We want to help you."

05-00:12:40

Lage: Wow.

05-00:12:42

Longmore: So they gave me the tuition for the first year—but not after that. So, every semester I would get to the point where I would say to myself, "Why am I doing this? I will never be able to get a job." There are all these, well, they call them work disincentives. I thought of them as work punishments, you're disabled and you need this assistance and they'll penalize you, they'll punish you if you try to be productive. So this went on for years, and every semester I would think, "Why don't you just forget this, and I don't know what you'll do, but." And then I would say, "Well, what about that thing that happened in the mountains?" You know?

05-00:13:26

Lage: So that was something that kept you going.

05-00:13:28

Longmore: And it still has, actually. Because I still feel like, well, that was a calling, that was a command, and there's a reason you're supposed to get a PhD and become a historian. I had no idea at that point, this is 1971; I had no idea about disability studies.

05-00:13:53

Lage: No.

05-00:13:53

Longmore: Or disability rights, or disability history. And in retrospect now, I see, well, that's really what my career—I mean, I think I've done some valuable work in early American history and that's mostly what I teach, but I—you know, all this other stuff went in the future. And it took a very long time to get anywhere. So anyway, I at one point around 1980, I was thinking, "I'm not going to make it at this." So I met this guy who was disabled who had worked in TV and we started talking about this idea of television, because there was an opening in the early eighties in L.A. in television regarding people with disabilities. There was an interest in non-stereotypical characterizations and casting and doing more programming, and so we thought, "Well, magazine shows are really popular and why not a magazine show like "People with Disabilities." So we planned this. We spent a good deal of time, I think I spent most of a year neglecting my PhD and working on that. In retrospect it was really foolish, but what happened was, in doing the planning and research for that idea, I ended up going to a lot of things in L.A., a lot of conferences and

meetings and workshops and lectures and met a lot of people and that was how I got involved in the L.A. disability rights movement.

05-00:15:41

Lage: That you really didn't know existed, probably.

05-00:15:43

Longmore: I hadn't had any contact with it. I was trying to do research to learn about topics and issues, and so I—for instance there were a whole bunch of workshops around the L.A. area on sexuality and disability that were done by a woman named Barbara Waxman, who is no longer with us but she became a really good friend, one of the first people I really got to know in the L.A. disability community. But the way I met her was I went to a workshop that she did and introduced myself. Then there was a conference at USC in, I guess, 1980 on disability in movies and television, and I had always been an avid TV watcher. I watched way too much TV, and I'd gotten interested in movies too so I went to this conference and met a lot of other people there and then, I forget how it got started, but I started to do a lot of public speaking; there'd be disability awareness days or weeks or months at various kinds of college campuses, and so I got invited to be a speaker at these things.

05-00:17:08

Lage: And here you talk about being shy. Was that a big step to become a speaker?

05-00:17:13

Longmore: No, because it's a performance. I mean, there are a lot of shy actors and they'll tell you that it's playing a role and it's not me so I, when I, when I would get up in front of an audience to speak it was a performance, it was planned, it was playing a role, and it was something where I was confident I could do it well. And actually it helped me get past my timidity in my interpersonal relations. So I started to develop a kind of basic public talk about disability issues and I used the media, since I had thought about that a lot, I used that as a hook, so I would talk about images on television in particular, or in old movies, and say, "Well, you know this particular characterization represents this sort of stereotype or this idea about disability." And that really worked because most of the people were familiar with these images. They'd seen them and they'd never really stopped to think about what they were saying.

05-00:18:31

Lage: Who were your audiences?

05-00:18:34

Longmore: Well, on these college campuses it would be students and some faculty and some administrators and maybe members of the public. In California and other states a very high percentage of people with disabilities who go to college go at least initially to community colleges, and a lot of these events were at community colleges. I think I spoke at every community college in the L.A. area and at some of the Cal States as well and at UCLA at one time or

another and sometimes several times over a period, over the decade of the eighties. So I did that public speaking and I got to know a number of people who were leaders in the L.A. disability community.

05-00:19:21

Lage: Mention some of the ones who may have had an influence on you.

05-00:19:24

Longmore: Barbara Waxman I mentioned—

05-00:19:25

Lage: Tell me more about Barbara.

05-00:19:27

Longmore: Barbara had already, in the late seventies, gotten connected with Planned Parenthood in the San Fernando Valley and started what I think was the first project at a Planned Parenthood for counseling for women with disabilities about reproductive issues. And she became a leading voice about romance and sexuality and reproduction for women with all kinds of disabilities, particularly physical disabilities. So we became good friends, I got to know Barbara right then, around 1980.

There were a number of independent living centers in the L.A. area and so I met a number of people there who were directors of centers. June Kailes from the Westside Center for Independent Living. Sooner or later I met Doug Martin who was one of the founders of the Westside Center and a policy expert on a national level who was working on the work disincentives issue. Carol Gill and her husband Larry Voss. Carol was a clinical psychologist who at that time had a practice in L.A. and then in the summer of '83 I met--oh, not in the summer--in the spring of '83 I met Harlan Hahn, who is a political science professor at USC, and he said, "I'm going to be teaching a course this summer," I'll come back to that, I sat in on the course and that resulted in my going to work at USC with Harlan in what would become disability studies.

05-00:21:20

Lage: Was—I would just think there'd be some kind of consciousness-raising on your part, to all of a sudden be involved with all of these movers.

05-00:21:29

Longmore: Yeah, yeah, there was. It helped me reframe a lot of things, it, it helped me *confirm* things I had thought but then deepen my understanding of things. A lot of stuff I had thought was personal to me turned out to be common and therefore not individual but social. A lot of problems I struggled with I realized were typical and didn't come from inside us but came from outside, like struggling to deal with the system, the social welfare system or the rehab system. It deepened my political take on things. What we talked about a lot was people with disabilities as a minority group—

05-00:22:22

Lage: Which you had been thinking.

05-00:22:24

Longmore: I had been thinking in those ways, but Harlan especially and then Carol Gill really deepened my thinking about that, I mean, interacting with them, thinking with them—Harlan had already written about this, and so I read some of his stuff and incorporated some of his key ideas into what I was seeing. Harlan was very influential in the early eighties in disability rights ideological development and William Roth, coauthor with John Gliedman of *The Unexpected Minority*, which I think I've mentioned.

05-00:23:04

Lage: You've mentioned that, but was he in that area?

05-00:23:07

Longmore: No, he was back East, but I read his stuff. And then Harlan—when I went to work at USC, the first year I was there was '83-'84—Harlan edited a special issue of *American Behavioral Scientist*, and Roth contributed a coauthored essay, Carol contributed an essay, and I did a little piece on language and disability. That was my first publication in disability studies. I mean, it's pretty simplistic as I reread it now. So it was all this activism mixed up with academic work by the mid-eighties.

05-00:23:51

Lage: Did Carol Gill bring any perspective that—

05-00:23:54

Longmore: Yeah, what happened was in '85-'86 Harlan went on sabbatical, and we had arranged for Carol to teach a course on the psychology of disability at USC and we were hoping to get it on permanently. While Harlan was on leave, Carol became the acting director of our program. So three days a week, Carol and I would get together to plan and strategize. But we also spent literally hours each of those three days just talking. And it was a two-person graduate seminar in disability studies. And that was a moment when I really crystallized a lot of my thinking. Carol is still one of the most important thinkers in disability studies and disability rights of anybody around, and I think she's read and learned from a lot less than ought to be the case. But that moment was, was central, was seminal for me that year.

05-00:25:09

Lage: What did she—I know it's hard to kind of think back and generalize, but could you characterize what views she brought—

05-00:25:16

Longmore: Carol has a really complex, sophisticated understanding of the experience of disability, in which—some disability studies scholars and disability activists want to minimize the significance of the physical and medical and just talk in terms of the social and political. And I'm certainly in favor of shifting focus to the social and political, because it was, it's so ignored, it's so neglected. And

Carol shares that view, but she's got a really sophisticated understanding of the interplay among all these elements. She doesn't try to explain away the physiological or the medical, but she puts it in a context that understands that even the experience of that physiological difference is embedded within a social and cultural and political context. So she understands interpersonal relations and social relations in that broader way. So she ends up with a complex, much more subtle, and I think much more real and realistic explanation of disability experiences. She doesn't try to minimize the inherent hardships in many disabilities, but that doesn't lead her to devalue people with disabilities or disability experiences. I think a lot of activists and disability studies scholars are afraid to talk publicly about some of those inherent problems or hardships.

05-00:27:14

Lage: They're afraid of the old pitying—

05-00:27:18

Longmore: Well, I think, I think one reason that a lot of people are afraid to talk about those things publicly and directly is the assumption, which is probably correct, that there are a lot of people in the larger society who will hear it and then misunderstand it, misinterpret it and use it to say to us, "Ah, see, I knew, your life is really a lot worse than mine, and you really are less human than I am, you're less of a person, and disability really is just inherently horrible," rather than understanding it in a larger context in which there are positive as well as negative elements and they're all wrapped up together; they're really ultimately inseparable, and that, as Carol has put it, there are lots of ways to be human and disability experiences are one of them. And she always understands these things in a psychological and a sociological and cultural context. I mean, she's very interested in identity formation, which as I've told you is an interest of mine from a historical perspective.

05-00:28:34

Lage: But you came as a historian and she as a psychologist.

05-00:28:37

Longmore: Yeah, and that was one of the things we had a lot to talk about, so, I, well, I'd like to think that I had some impact on her too in terms of her thinking, so we really cemented a very deep intellectual friendship as well as emotional friendship in that year we were together at USC. And in fact, there have been a number of times since she's been at University of Illinois-Chicago when she's wanted me to come back there so we could work together again, and it's really tempting to work with—

05-00:29:10

Lage: Go back there with an appointment?

05-00:29:12

Longmore: Yeah.

05-00:29:13

Lage: Not just as a visitor.

05-00:29:15

Longmore: No, yeah, well, both, but hopefully permanently, but I couldn't live in that climate, so I never pursued it. Harlan, Harlan's writings influenced me a great deal in that moment as I said, Bill Roth's, and there were other people who were writing at that time so I was trying to formulate my own thinking. Irv Zola came a couple of times and visited us at USC. In the mid-eighties he had started what was then called the *Disability and Chronic Disease Newsletter*. It eventually became the *Disability Studies Quarterly*, which is one of the top journals now in the field of disability studies. Also, he and other people, some disabled, some not, had formed a section within the Western Social Science Association, people basically interested in the academic study of disability. That eventually evolved to become the Society for Disability Studies, of which Irv was the founder. So I got to talk to Irv and get to know him the several times he was with us in L.A.

05-00:30:35

Lage: Where did he, what was his home base?

05-00:30:37

Longmore: Irv was at Brandeis in medical sociology, and Irv and Harlan were good role models in one respect. Here were guys who had made their reputations in their fields, sociology and political science, in areas outside disability. I mean, with Irv it was medical sociology and things about hospital settings and medical professions and all that, but eventually, he had had polio, he moved on to look at disability. Harlan had worked on black politics and civil rights, and in fact, I had read a historical piece he had written about politics and race in late-nineteenth century, post-Civil War Iowa. I had read that in graduate school in a book on using quantitative methods in historical studies. And then I meet Harlan, and by now, by the time I met him, he had moved over toward what would become disability studies. So here were two guys who had cut their teeth on other things, or made a reputation on other things, and I was poised to try to do that in early American history, and so they became kind of examples of it being possible and even appropriate for me to add disability to my historical work.

So it's while I was at USC that I first started to think about disability history, and all the people who were involved in the early- to mid-1980s in what would become disability studies in the United States were people who had actually trained to do something else and mostly had done something else. They were policy people, they were social scientists; I was the only historian. There was nobody from the humanities at that point, as I recall, and we all came into academic disability studies out of disability rights activism. And I think what we started to think—I know this was what I was starting to think—well, any movement needs people to do critical research and analysis in order to formulate theoretically and in terms of empirical research whatever tools

the movement needs to deepen its analysis, its critique of the existing system of things and to set out elements of a sophisticated agenda. And I think that's what we thought we would be doing.

05-00:33:41

Lage: Were you seeing women's studies and ethnic studies as any kind of model?

05-00:33:45

Longmore: Particularly black studies, particularly that and the civil rights movement, and black intellectuals, I think were, well, I had already been influenced by them, like myself, I certainly know Harlan was, I think a lot of us were taking—feminism was not a big part of disability studies in the early-eighties. It would come in the nineties.

05-00:34:09

Lage: Because I was thinking of women's studies departments, with—they maybe had a similar agenda.

05-00:34:14

Longmore: I—there really wasn't in the early- to mid-eighties a lot of thought I think on the part of a lot of people about developing whole programs and departments. At USC between '83 and '86, what Harlan and I talked about what trying to develop course offerings in what we called the Program in Disability and Society. We didn't have the term "disability studies." I know that at Suffolk University in Boston, already for several years, David Pfeiffer, who would later become the editor of the *Disability Studies Quarterly*, was developing courses.

05-00:34:56

Lage: Yes. Were you in touch with him at all?

05-00:35:00

Longmore: I wasn't in touch, but Harlan knew him. My job in the first year at USC was to go around the university and make contact with faculty, department chairs, administrators to say, "This is what we're trying to do, and students in your department, or in your major, or in your sphere of work really would benefit from courses on the subject of disability and society because the work they're going to do when they come out of here with a bachelor's degree or an advanced degree will bring them into contact with people with disabilities." I contacted that first year something like eighty-five faculty or administrators, and some of them didn't want to talk to me but most of them did, and I would go to their offices and do—talk about getting over my shyness!

05-00:35:59

Lage: Yeah, right! [chuckling]

05-00:36:01

Longmore: —cold calls, "Hi, I'm Paul Longmore. I'm the program specialist in the Program in Disability and Society and what we're doing is—can I make an appointment to meet you to talk about what we're doing?" Well, you've got a

lot of really busy academics. They're kind of reluctant to give up an hour of their time, but, a lot of people did and we—

05-00:36:22

Lage: How did they respond? It was a new idea—

05-00:36:24

Longmore: Some people said, “Well, yeah, it’s a great idea but the course requirements in our major, especially for advanced degrees, are solidly booked up already, there’s no room for anything.” So I developed a strategy for that. Harlan had a course in political science with a very unsexy title of “The Politics and Policy of Rehabilitation,” or “The Politics and Policy of Disability and Rehabilitation,” something like that. Well, God, who’d want to take a course from that title? So I talked to the chair of the undergraduate general education curriculum committee, and I said, “There’s this one area of GE requirements called American politics and government. Now, this course that we have covers a lot of that stuff, and it’s a good case study of one dimension, one area of concern of American politics and policy-making, and we would like to have it meet the GE requirement in American politics and government.” And they said, “Yeah, okay.”

05-00:37:49

Lage: Was it framed that broadly that it—

05-00:37:52

Longmore: Well, we reframed it.

05-00:37:53

Lage: You reframed it.

05-00:37:54

Longmore: And then I changed the title of the course. I called it “From Stigma to Society, the Politics of Disability in America.” And then I had a student, an undergraduate student, who was just a whiz. Fortunately for us at that moment registration for courses was not yet computerized. All registration now in most places is all online. Well, it was still the old system. You go into this big room in the gymnasium, and there are all these tables set up and you have to pick up a piece of paper about a course, and you have to sign up for it right there. So you go in there, and there are all these tables of undergraduate students sitting there going through the course catalog, looking for courses they can take that’ll fulfill their GE requirements. So I went in there and this undergraduate student, Chris, went in and she was the real salesperson, much more than I was. We’d come up to a student, we did this separately, we’d talk to a student and say, “Have you fulfilled the GE requirement in American politics and government?” “No I haven’t.” “What’s your major?” They’d tell us their major. “Well, here’s a course that is actually advantageous not only because it fulfills the GE but it also will help you with your major, because if you want to be a nurse, or you want to be a school teacher, you’re going to get kids with disabilities in your classroom; you want to be a lawyer, well, you’re going to

have to deal with disability rights issues at some point. It's becoming really important." Whatever it was. We tried a hook—you know, "You should think about taking this course."

The result was that, I think it was over two years, we tripled the enrollment in the course. It was fifteen when we started, the Poli Sci department was about to axe the course because Harlan was struggling to get the minimum enrollment. But in two years there were forty-five students in the class. And then we started to offer it not just once a year, but every semester, and then we went to the nursing program. I went to the nursing program and talked to the head of that and I said, "You know, your students really could benefit from this." And she said, "Well, the requirements are all fixed." And I said, "They have to take this GE as undergraduates." "Oh, that's true." "But they—you're offering it the fall semester and they're booked up in the fall semester with their required courses." "So," I said, "We'll offer it in the spring as well." So I taught it, and I got about eight nursing students in that class the first time. So we started to recruit people, and in the year that Carol was there, she and I developed a seminar in which we drew in some faculty and some grad students interested in disability, these were people from all over the university. These people would never talk to one another, and they had a similar interest. And we would have research presentations, and people started to get to know each other, they started talking about collaborations.

05-00:41:17

Lage: What fields were they, were you drawing from?

05-00:41:19

Longmore: Any discipline you could think of they came from.

05-00:41:22

Lage: But they had some tie-in to disability?

05-00:41:24

Longmore: Some interest—you know, one of the things I did there, and I later did this at Stanford and then at San Francisco State. I went to the course bulletin and I just looked at every single course description. I mean, there were thousands, and I thought, well, here's a course that definitely deals with disability. Who teaches it? Here's a course that probably deals with disability; here's a course that may implicitly deal with disability, and they don't even know they're dealing with disability; here's a course that ought to deal with disability, and I would go see these people, and I, I—

05-00:41:59

Lage: You became an evangelist, Paul!

05-00:42:01

Longmore: [laughter] Yeah! That's right—well, I used to say that first year to Harlan, "Harlan, we're doing the Lord's work." So I ended up with virtually an entire year at the Huntington.

05-00:42:13

Lage: How was Harlan as a teacher?

05-00:42:16

Longmore: Okay, now, this I want withheld.

05-00:42:20

Lage: Okay.

05-00:42:22

Longmore: Okay. This part—whatever I say now gets suppressed until both he and I are gone, Okay?

05-00:42:28

Lage: That's fair enough, you've got it on the tape.

05-00:42:29

Longmore: Okay. I am always amazed that the political scientists I've known are often really incredibly naïve about power and how it works, and I first learned this dealing with Harlan. In terms of teaching he was not a good teacher. He did not prepare and he got a really negative reaction because of that. And for a while I co-taught with him and fell into his bad habits, and then I taught alone and developed a course for myself and did a much better job.

05-00:43:13

Lage: That must have been discouraging. Here you're, you're recruiting—

05-00:43:14

Longmore: It was, it was very discouraging. What was really more discouraging was his lack of strategic sense and the emblematic moment came late in the second year I was there. I got us an appointment with the dean of the College of Education and we sat down with him and we said, "You know, you've got these master's and doctoral students in various fields of education, among which are educational administration. We could develop a course for you on disability-related issues, because your graduates are going to all have to deal with it whether they're classroom teachers or school administrators—

05-00:43:58

Lage: Because it was big then, you had IDEA [Individuals with Disabilities Education Act], and—

05-00:44:00

Longmore: IDEA—yeah, well, this is, yeah, this is ten years after IDEA, and it's still pretty controversial, and this guy immediately recognized that this was really important stuff, and he said, "Yes, I want this, I want you to do this, and moreover, what I would recommend is you need an advisory committee for your program, and I will serve on that committee, I will volunteer to serve on that committee. You need to get people from other schools and departments and get them on your advisory committee to plan all this, not just courses for the School of Education but other courses."

So we left his office and Harlan said to me, “We’re not going to do that. We’re not going to have that advisory committee.” I said, “Why not?” And he said, “Because if we set up an advisory committee with all these other people on it, they’ll have all the power and we’ll have none.” I said, “Harlan, they’ve got all the power, and we have none. And the only way we’re going to get the power is if guys like that help us get it, and he’s willing to help us get it. The other thing is, if he volunteers to be on an advisory committee, then other deans, other departmental chairs, will not say no.” And in fact, that’s what happened the next year when Carol and I set up the seminars, and I was doing more recruiting. The head of the School of Nursing had said to me—she had blown me off the first time I talked her. Now, she finds out that all these other people were getting on board. Now she—

05-00:45:45

Lage: So did you talk Harlan into the board?

05-00:45:47

Longmore: No, no, no.

05-00:45:48

Lage: But you did it with Carol.

05-00:45:49

Longmore: Well, we didn’t have the board with Carol, because Harlan was coming back, and he didn’t want it. So anyway, the School of Nursing person, she finds out these other people were getting interested, she doesn’t want to be left out. She doesn’t want something later on imposed on her and her program, so she asks me to do something for her students. And this is what would have happened if we’d gotten an advisory board, and we never created those courses for the School of Education, we never did it.

05-00:46:18

Lage: Oh, you didn’t.

05-00:46:19

Longmore: No! And so, part of the strategy, I thought, was eventually I’d get to be at least an instructor, we would try to work it out that I could get hired into the History Department and teach disability history, among other things. I got to know people in history. I was teaching the course in the spring semester. He was teaching the same course in the fall, but I was starting to get more students. I was more popular with the students. He comes back from his sabbatical, and he announces to me that, “You, Paul are not going to do any more teaching. And I have seven grant applications that I want us to apply for.” Which meant I was going to write—that was one of my other jobs, writing grant applications. And it was really hard because we were writing to federal agencies that always funded traditional kinds of rehab stuff.

05-00:47:27

Lage: Like NIDRR [National Institute on Disability and Rehabilitation Research]?

05-00:47:29

Longmore:

Well, NIDRR was one, yeah. And we never got any money from them because what we were doing was so foreign to the way they thought about disabilities. We were trying to retool their thinking. I mean, it was another decade before they, even under Kate Seelman, started to think about disability studies in the way we were talking about it in the mid-eighties. So anyway, he comes back and this is now summer of '86 and he says to me, "You're not going to do any more of the teaching. I have these seven grant applications I want to apply for," which meant I would write the grant applications. I looked them over. The only one I can remember was something about studying social networks of teenagers with disabilities, and all the rest were similar to that.

05-00:48:20

Lage:

Similar kind of sociological or—

05-00:48:23

Longmore:

Yeah, so I said to him, "Harlan, you're a political scientist, I'm a historian. This is social psychology or sociology. We're not qualified to do this stuff. And besides that, what I didn't say was, "I'm not interested in doing that stuff." And nonetheless he wanted to do that. So I thought, well, okay, that's it, that cuts it, I'm done.

05-00:48:49

Lage:

Do you think he was jealous of your, the way you were blossoming?

05-00:48:56

Longmore:

Yeah, I think so. So, here's another moment when I took a big leap of faith, I that summer had—

05-00:49:11

Lage:

What year would this have been?

05-00:49:12

Longmore:

Summer of '86.

05-00:49:13

Lage:

Of '86, Okay.

05-00:49:15

Longmore:

I had met the director of the Huntington Library.

05-00:49:20

Lage:

Who was—

05-00:49:21

Longmore:

Bob Middlekauff from the History Department at Cal. He had taken a leave from Cal for a number of years to direct the Huntington. Do you know Bob? He is the most—

05-00:49:32

Lage: A bit. I'm hoping to have him be my next interviewee in the History Department series.

05-00:49:40

Longmore: Really? Oh, he's a wonderful person. He's one of the most decent people you'll ever meet. I met Bob that summer, I forget, I was at some, I guess, early Americanist meeting probably at the Huntington, and he asked me about myself and my work. I had finished my PhD at Claremont, by now it was two years earlier. I wanted to turn my dissertation into a book, so when I met him he said to me, he asked me about myself, my work and he said, "If there's anything I can do to help you, just give me a call." So after this list of seven grant applications that Harlan gave me, I called up the Huntington, and I asked to speak to him, and I said, "You said that if you could do anything for me I should call you. Well, I'm out of a job and I'm looking for something to do." He said, "Let me call you back." So he called me back in a few minutes and he said, "I can give you two months of a fellowship." That was all, two months, and it wasn't much. But I quit the job.

05-00:50:53

Lage: It was enough to make you quit the job.

05-00:50:56

Longmore: Yeah. So I wrote Harlan and I said, "You know, I think we're going in different directions. It's not what I want to do, and so you need to find somebody else to replace me." And just before I left USC, I get a call from our dean, who had funded the program that I had worked in for three years, and it was interesting. I made an appointment to see him. He said he wanted to talk to me about the program, its future. I talked to a friend of mine, a guy I'd gone to college with, a guy who'd been a roommate for a short time. He was a college professor, and he said, "Whatever you do Paul, don't go in there and run down the guy you're quitting because deans don't want to hear about that. He wants to hear what you think about what ought to be done, so I sort of listened and went into the meeting. I was so angry and Dean Bohannon says to me, "Paul, what can I do about the Program in Disability and Society," and I started to criticize Harlan, and he cut me off and I thought, ah, Dale was right, you know. You just talk about what you would do. And that's basically what the dean said, "What would you do?" And I told him I had a plan, I had a strategy and he said, "I think you're exactly right. That's what we ought to do. If there's a way I can get you back here, I will bring you back." Well, unfortunately, a year or two later he quit being dean, and then he retired so I never went back.

05-00:52:41

Lage: It's interesting, though, that he had that level of concern and support.

05-00:52:44

Longmore: Well, he saw, I mean, one of the things Harlan had done that was really effective—Harlan can be great at a certain kind of sales, a certain kind of

presentation. He has a very authoritative presence. He had this deep baritone voice, and he could be really powerful and even eloquent and he had gone to Dean Bohannon before I ever got there and laid out this vision, and the dean immediately grasped that it was really important. And in fact, Harlan at that point was referring to what he wanted to do as a study of the philosophy of human differences or was it the history of human differences, something like that. I stole that title for a course I taught later, here at San Francisco State. So anyway—

05-00:53:42

Lage: So that appealed to you, that characterization.

05-00:53:45

Longmore: Oh, I think it's exactly right. I mean, about some things in terms of his ideas, Harlan was absolutely right on and seminal. The problem was strategic, and organizational. He didn't know how to bring these things off, and in fact, he became obstructionist about it. And so after I left, he hired somebody else who lasted another year or two, and then the program folded, and the new dean didn't want to support it. There was no reason to, it wasn't going anywhere. Harlan has been alienated from his own department in the university for a very long time, and he's still in trouble with them. So anyway, so I went to the Huntington for those two months and learned about a fellowship from the H.B. Earhart Foundation, back in, I think in Michigan, and they gave me nine months. So I ended up with virtually an entire year at the Huntington.

05-00:54:48

Lage: Did you have interchange with Bob Middlekauff during that [time]?

05-00:54:51

Longmore: Oh, yeah, yeah, I saw Bob a lot and Bob—I was turning my dissertation into a book, so this is now '86-'87 and Leonard Levy, who was the chairman of the History Department at Claremont, was on my dissertation committee, and he tried to help me get the book published. I used some of his contacts. None of those panned out. Bob Middlekauff said, "One of my former students is the," what is it, "associate director of UC Press, so let me talk to her." And he got her to read my manuscript, and UC Press bought the book. So, yeah, it really paid off to go to the Huntington, and then I stayed on for another couple of years and continued to do research with the idea of doing a second volume on George Washington and his career and image, to finish out his lifetime hopefully with another book. And those three years at the Huntington were just wonderful, I mean, it's just the most glorious place for a historian to do research.

05-00:56:08

Lage: Now why is that?

05-00:56:10

Longmore:

Because they've got everything you'd want, just about, and you get to meet scholars, historians, and people in other disciplines, particularly literature, from all over the country and all over the world. I met some really wonderful people, some of whom became real good role models for me, and the Huntington is just a place of peace and quiet and they were very accommodating for me. They gave me a little room at the end of what's called the Special Reading Room. It's really Rare Books and Manuscripts. There's three small rooms right at the end with windows, and it's for people who want to collaborate on a research project; you can go in there and you talk to one another. Well, I used a dictaphone to dictate my research notes, so they gave me the largest of these three little rooms, and I set myself up in there for three years and I had my dictaphone there, and I had the books I was using, and they would bring me the rare books and manuscripts. And I read a lot of stuff, and it was really just a wonderful place to do research. So I switched back then more toward early American history.

05-00:57:35

Lage:

Now, because you'd had all this thinking and your discussions with Carol Gill and everything, I'm just wondering how that impacted as you wrote about American history. We talked about that a little bit last time, the overlap, but now you see, as you're talking, I see that the time was overlapped, your writing—

05-00:57:53

Longmore:

Oh, yeah, yeah, well, I no, I mean, while I was at USC, I started to write some disability-related stuff and that continued even after I left there and I wrote about not just disability history—well, all my early work in disability studies was from '83 on up to the end of the decade.

05-00:58:17

Lage:

But did it also kind of affect how you were writing the George Washington book and the second volume that you were working on?

05-00:58:22

Longmore:

Well, this was the period in which I did realize that there was a kind of hidden connection. I had mentioned about identities and values and social themes and I realized that there was—

05-00:58:37

Lage:

So you were conscious of it.

05-00:58:38

Longmore:

I became aware of it. I don't know that it caused me to write the Washington book any differently, but I became aware of it, yeah, yeah.

05-00:58:47

Lage:

I'm going to stop us now because we are at the end of the tape.

[Audiofile 6]

06-00:00:00

Lage: Recording on tape number six. Okay, Paul, you said you thought of some things that—

06-00:00:05

Longmore: Yeah, well, first of all, I finished my PhD in '84 at the end of my first year at USC and then in '86 when I left USC I went to the Huntington. [this portion of the interview has been sealed until 2025] I was, still living on SSI and scrimping to pay for transcription services so I could do my research. And that really slowed me down. I mean, there would be weeks and even some months that would go by and I wouldn't have any money to pay for transcription, so why dictate notes, when you can't have them transcribed? So I really slowed down a lot, but still I was—I had turned the dissertation into a book during those next three years, I published other articles in the area of disability about what would become disability studies. I mean, a pretty eclectic set of topics, some historical, some cultural, some about bioethics, some popular, had a number of reviews published on movies in the L.A. Times and some op-ed pieces published in various newspapers.

06-00:01:37

Lage: Yes. Some of those are in your book.

06-00:01:39

Longmore: Most of that stuff is in the book one way or another, yeah. Now, let me backtrack. Early eighties in L.A. in terms of disability rights activism, I mean, all through that decade I was very involved with disability rights activism.

06-00:01:57

Lage: But you really haven't said what you did as an activist.

06-00:01:59

Longmore: Yeah, well, I mentioned the public speaking, that was one big thing. I got involved with what was called the Media Access Office, which is still there. I was on their board. They were an office set up in Hollywood to initially help actors with disabilities get roles. So they did consulting with casting directors, but they also got interested in stereotypical characterizations or trying to help producers and writers not do stereotyped characterizations, and that's where I came in. I did some consulting on that. I read some scripts. They gave out awards every year. I drafted the guidelines for the judges for those awards. Unfortunately, the judges were a mix of people without disabilities from the industry and people with disabilities from the community, and certainly the ones from the industry had no understanding of disability issues. And a lot of the folks from the disability community didn't either. So I kept wanting to grab everybody by the shoulders if not the throat and shake them and say, "Do you know a stereotype when you see one?"

06-00:03:17

Lage: Even people from the community.

06-00:03:19

Longmore: Oh, yeah.

06-00:03:19

Lage: I mean, did they take—when you say the community—

06-00:03:22

Longmore: Well, one—my favorite example of how little understanding there was was one year there was a show submitted in nomination for one of the awards, and it was about a person with a broken leg, and I said, “That’s not a disability!” [chuckling] I kept saying to people involved on the board, “We’re giving out these awards, and nobody is ever told why they got an award or why they didn’t get an award. We never say, ‘Look, this is what we’re looking for; this is what we want to reward and honor, because we want things to move in this direction.’” Well, they didn’t want to do that, they were too timid. They were just so grateful that these producers actually submitted videotapes, and I thought, well, this is really a waste. So we had these big dinners in Beverly Hills or Century City or someplace like that, at the Century Plaza Hotel, these big banquets, and all these celebrities would be there, and it was kind of intoxicating.

06-00:04:31

Lage: Yeah, if only one of them could have funded your fellowship!

06-00:04:34

Longmore: Well, but it didn’t, it didn’t change anything. I mean, so after about eight years of this I finally resigned, you know. At one point I met a producer, one of the producers of the TV series, *Quincy*, which was about a medical examiner starring Jack Klugman in the title role, and they had done this wonderful episode about a doctor who was causing the deaths of disabled newborns. And Quincy goes after him. And there’s a second story line about a young man with Down Syndrome. He’s about twenty-three and he’s in a training program to learn how to live independently, and at the climax of the story he takes several buses, and he shows up at the court for the hearing. The people who have been training him are already there for the hearing, and they say, “How did you get here?” And he said, “Well, I followed the directions you taught me about how to take the bus.” And Quincy says, “I want to put you on the stand.” So he puts him on the stand, and this guy gives this eloquent speech about prejudice against people with developmental disabilities, and the doctor who has been killing these disabled newborns who have Down realizes what he’s been doing.

So I met the guy who wrote this, one of the producers, Michael Braverman, who later went on to produce a series called *Life Goes On*, in which one of the members of this family is Corky, a guy with Down Syndrome, and they cast an actor to play that—that was in the future—so I meet Michael Braverman at this dinner and I said, “Your show, that episode, was just extraordinary. I really appreciate it.” He said, “Would you like to meet Jack Klugman?” So I

said, “Okay.” So he takes me into the VIP lounge and I meet Klugman and the other producers. A month or so later I get a call from one of the producers. “We’ve got this script, it’s about a physically disabled character, we don’t know what to do with it; it’s got problems. Can we send it to you? Would you read it and give us some feedback?” “Sure.”

So they send me the script and then they say come over to Universal and meet with us. I go over to Universal, they had what was called the Black Tower where all the offices were, where the production company is. I sit there with Klugman and these producers, and they say, “Okay, tell us what to do.” I start telling them what’s wrong with the script. “Yeah, yeah, yeah, we know, we know what’s wrong, just tell us what to do to fix it.” The writer’s not there. They’re tape-recording this, so I said, “Well, I mean, you could do this, you could do that.” One idea I had was, well, this guy had a bad relationship with his father and now he’s pretty angry about that, and he and Quincy are investigating the death of this disabled newborn, and so he thinks that the father killed the kid. So there are many relations to his own upbringing.

For some reason, that’s the one idea the writer picked up on. They rewrite the script; they don’t show it to me. They produce the episode, it airs, and it’s worse than the script I read! [laughter] I mean it’s just horrific! This guy is the most enraged, bitter disabled person you’d ever meet. And at one point he’s sitting there after he’s been investigating this newborn’s death, and he comes home, plops down on his sofa. He’s got these Canadian crutches, the forearm crutches, and he sits there and he looks over at this photo of his father on the end table, and they cut back and forth between the picture and this guy and each shot is closer, a tighter shot, and he’s getting more and more enraged, and suddenly he takes the crutch and he smashes the picture of his father!! And my aide, a guy named Steve from New York, turns to me at that point, and he says, “You consulted on this script?” And I said, “Yes.” And the episode ends and Steve says to me, “Wow, they sure screwed you people.” [laughter]

So there are protests from the disability community, it gets in *Daily Variety*, and the executive producer responds to the criticisms from the community by saying, “Well, we had a paid consultant on it, Paul Longmore.” And I thought, “Oh, man, what have I gotten myself into!” [laughter] So it was experiences like that, I thought, this is just a waste of time. Every year, Michael Landon’s people would contact the Media Access Office, and they would want him to get an award. He had, in *Highway to Heaven* and before that *Little House on the Prairie*, he had produced so many stereotyped episodes involving characters with disabilities. Every year I vetoed him getting an award. Finally I resigned from the board, and the next year they gave him the award, and they *named* the award after him! Anyway, I just, that was when—

06-00:09:47

Lage:

This is your Hollywood connection.

06-00:09:48

Longmore: Yeah, that's my Hollywood connection, but there were two other issues. One was about work disincentives, because I had been, even after I got my PhD, how am I ever going to get a job? So I was at the Huntington doing research. It was January of 1988; well, I guess this is in the essay, in *Why I Burned My Book* so I won't go into a lot of detail, but here's some stuff that I didn't put in the essay.

06-00:10:19

Lage: Yes, good.

06-00:10:19

Longmore: The year of 1988, I went to the director of research at the Huntington, Martin Ridge. He's gone now. He had a developmentally disabled son, and so Martin had taken an interest in me. I forget how it developed, but Martin offered me a fellowship. I think it was going to be for a year. Well, by now, just a few months earlier, Congress had passed legislation making what's called SSI 1619, it's a new section in the law, permanent. SSI 1619 would permit a person with a disability on SSI to go to work and earn up to a certain amount and not lose eligibility and therefore lose Medi-Cal or Medicaid or other kinds of benefits, and that's what I had been waiting for. It was supposed to take effect that next July of '88. So Martin offers me this fellowship, and I said, "Oh, that's great, Martin, that would really help, but I think I'd better check on this." So I call my friend, Doug Martin, who had been one of the architects of the new law, and I said, "Can I take this fellowship under 1619?" Because under the old rules I couldn't. [this portion of the interview has been sealed until 2025] Anyway, Doug called me back the next day and he says, "No, not only can't you take that fellowship, but I found out also, your book on Washington is going to be published next fall, and if you get any royalties, that's unearned income too, and it's not exempted under SSI 1619."

06-00:12:12

Lage: But you must have had a certain level that you could earn without losing benefits.

06-00:12:15

Longmore: Well, oh, very little. If it's earned income you can go up a lot higher, but unearned income, every dollar counts against you, so that's when I started a whole quest to get it changed, and that's what culminated in the book burning the next fall. So work disincentives is an issue I'd been addressing, and it really culminated right at the end of the eighties.

The other issue I started to work on early in the eighties was physician-assisted suicide. In 1982, Carol Gill, and her husband Larry Voss, and Barbara Waxman, and I—and some other people, Diane Coleman, who later founded Not Dead Yet—we all got involved in the first Elizabeth Bouvia case. She was in Riverside County, that's in the book too, so I don't need to go into it—

06-00:13:11

Lage: Right, it is, but—

06-00:13:12

Longmore: I came to write that piece [in *Why I Burned My Book*] late in the eighties, but we had gotten involved in the first round of litigation, and then we got involved in the second round a couple of years later. I wrote op-ed pieces in various newspapers. We formed the Disability Rights Coordinating Council, a small group in L.A. We got ourselves a lawyer of our own to try to get into that first case, and we all went down to Riverside County courthouse for the hearing. The press didn't want to talk to us. We went to the ACLU of Southern California, which had given her legal representation.

06-00:13:51

Lage: You picketed the ACLU.

06-00:13:53

Longmore: We picketed them. We went to their board meeting; a number of us spoke to the board. We were just crushed by the prejudice we heard from that group.

06-00:14:06

Lage: What kind of interchange. Do you recall?

06-00:14:09

Longmore: Well, they had rules about how to conduct their board meeting. Board members spoke, and then some of our people got to speak. So they spoke after the board members spoke. There was no chance for an interchange. Only two of the board members supported us, and what they basically said was, "You should listen to these disability rights community leaders." All we heard from the rest of the board was, well, I remember one guy saying, "I will not make Elizabeth walk through the burning coals of hell," meaning living with her disability, you know. We had all been, we were kids who came of age in the sixties; we thought of the ACLU as the champion of people who were oppressed, and here they didn't begin to understand our issues. And they thought they did. That was the thing; they thought they did understand. I debated people from the ACLU repeatedly during the eighties in L.A. about the assisted suicide issue.

06-00:15:16

Lage: In a public forum?

06-00:15:18

Longmore: In a public forum, yeah. I debated Derek Humphrey from the Hemlock Society on public television in L.A. in the early eighties.

06-00:15:27

Lage: And what was his understanding?

06-00:15:29

Longmore: Oh, he was all in favor of assisting Elizabeth Bouvia to die, yeah.

06-00:15:33

Lage: Did he ever grapple with questions related to disability?

06-00:15:37

Longmore: No, they don't begin to understand disability issues. They didn't understand what we were talking about. Some of them are fundamentalists about libertarianism. So one guy I debated late in the eighties—I would talk about the healthcare system and health insurance and discrimination against people with disabilities in the healthcare system, discrimination in society at large, the deep devaluation of the lives of people with disabilities. Right down the line, everything I said he agreed with, and then at the end he said, "But we still have to support the individual's right to choose, where anybody with a disability who wants to die, their right to choose. "Wait a minute, I thought we had already established that the whole idea of individual choice for somebody so oppressed is just spurious." No, no, they just didn't get that.

So we came out of that board meeting, this would have been, I guess '82, we came out of that board meeting just crushed, just brokenhearted by this. So, several of us joined the ACLU, which we hadn't belonged to, and we got on their right-to-die committee, and we confronted her lawyers right there in the meetings, and it didn't have any effect. So I wrote about this issue off and on all through the eighties. I did various—some of the articles reorganized into the second essay called "The Resistance [the Disability Rights Movement and Assisted Suicide]" that's in my book. That's really based on things I wrote, or speeches I gave, or testimony I gave in the eighties and nineties and even beyond.

06-00:17:26

Lage: Did you ever actually meet Elizabeth Bouvia?

06-00:17:28

Longmore: Not directly. We encountered her at some, a little distance. She didn't want us around. She really resented us, because we were telling her how she should live her life. I interviewed her husband for the article I wrote. I interviewed her rehab counselor. The rehab counselor was absolutely clueless, and this was a person with a disability too. I interviewed—

06-00:17:54

Lage: What about the husband?

06-00:17:55

Longmore: He had a bit more of a grasp, and he told me, they both told me a lot of stuff that you couldn't have gotten anywhere else, um—

06-00:18:07

Lage: About—

06-00:18:08

Longmore: Her.

06-00:18:09

Lage: The way her life had—

06-00:18:10

Longmore: What had happened, things that—in the two years leading up to her first bid to end her life, I mean, she had gone through an enormous amount of stuff: a miscarriage, DR [Department of Rehabilitation] cut her off, she got discriminated against at San Diego State in the social work master's program, her mother was diagnosed with cancer, her brother drowned, her marriage—she got married, she got pregnant, had a miscarriage and then they broke up—in two years, so there was a lot of stuff going on.

06-00:18:48

Lage: How significant was her impairment?

06-00:18:49

Longmore: Pretty significant. She was a quad—she is a quadriplegic due to her cerebral palsy.

06-00:18:55

Lage: And is she still alive?

06-00:18:57

Longmore: Yeah, she's still alive, yeah. I don't know where she is.

06-00:18:58

Lage: So she didn't win her case.

06-00:19:00

Longmore: She didn't win the case to have anybody help her directly to die. What she wanted was to starve herself to death, she said, and she wanted them to sedate her so that she could do it— See, she wasn't on any kind of ventilator that they could have disconnected, although the lawyers said, "She doesn't currently require any life support, any artificial life support, except for her wheelchair." Oh, wheelchairs aren't treated as life support.

06-00:19:30

Lage: Hmm.

06-00:19:31

Longmore: In the late eighties, not too long before I left L.A., I debated, I did a debate at the USC medical school with a doctor who was treating her there who said he wasn't sure if she had arthritis, but he put her on a morphine drip anyway, and he said some of his staff said, "Well, what if she becomes addicted?" And he said, "I said, 'So she becomes addicted, she's not going to exactly break into my house and steal my stereo.'" And I thought, well, that's a real contemptuous attitude toward her life—what does it matter if she becomes a morphine addict, she doesn't have a real life anyway? So there was that.

Anyway, late in the eighties, '89 to be specific, two other cases came up. Now I've written about these too, but what I haven't written about is the personal effect it had on me.

06-00:20:33

Lage: Yes, that's what I'd like you to talk about.

06-00:20:36

Longmore: The summer of '89—this is now my third year at the Huntington—that summer I was going through newspapers from the 1790s and looking for material about Washington who was then president and I was finding the kinds of stuff that historians dream of. In July I heard about this case in Michigan, David Rivlin, who was quadriplegic and a ventilator user from a spinal cord injury. He was on a ventilator, and he had gotten a lawyer who went to court to get him sedated and disconnected so he could die, but he was stuck in a nursing home. So somebody contacted me and said, "Could you look into this and write about it?" So I published an op-ed piece in the *Detroit News* about this and I was really troubled by the whole thing. I was—

06-00:21:47

Lage: It hit closer to home, maybe.

06-00:21:48

Longmore: Well, here I was trying to do this research, and I couldn't stay focused. I couldn't concentrate. I would have to leave the library, and I wandered through the botanical gardens—some of the most gorgeous botanical gardens in the world. I would just wander, you know. And this went on for a couple of weeks, and I said to myself, "What are you doing?" And then David Rivlin died. A doctor helped him die, and one Friday I was watching CNN and saw a Detroit TV reporter, who was paraplegic and African American riding a sports wheelchair interview Rivlin, and this was the guy who said to Rivlin, "What do you think of society's attitude toward people with disabilities?" And Rivlin said, "It sucks. Transportation, attitudes, financial help—it's all bad." And then he said that he hoped that his death would help other people to get the help they needed so they wouldn't get so despairing.

And I watched that, and that whole weekend I said to myself, "What are you doing? People are dying, and you have the luxury of doing this research?" That was in July and then in early August I get the call from the same person who says, "There's this other case in Atlanta—Larry McAfee, another quadriplegic who's on a vent and *he* wants to die, and again, I've recounted that in the book, so I won't go into the details about the case, but Mark Johnson who is with ADAPT, who's a disability rights leader in Atlanta, I talked to him on the phone to get some details about it and he said, We're going to file an amicus in the case." I quote him in the essay I wrote, he said, "You know it would help, Paul, if you wrote an op-ed piece about this." So I did. And it got published in the *Atlanta Journal- Constitution* and then I got asked to be on the *Today* show opposite the lawyer representing Larry

McAfee. They wanted to fly me to New York to do six minutes on the *Today* show and I said, “No.” So they sent a limousine over and I went at 3 a.m. over to Burbank and stood there in front of a camera with an earpiece that gave me a connection to Jane Pauley and this lawyer in New York, but it was like a really bad telephone connection, and Jane Pauley’s producer had called me earlier in the week and said, “What are you going to say.” I told them what I was going to say, the points I was going to make. She asked me the first question, I responded, and then she didn’t let me talk again for the rest of the six minutes, and she tried to make all of the points I had tried to make.

06-00:24:59

Lage: She tried to make them?

06-00:25:00

Longmore: Yeah. And did, of course, a far poorer job than I would have done because she didn’t really understand the issues. Nonetheless I had some kind of impact because the lawyer called me later that day. He was an aviation lawyer who took this case pro bono; he knew nothing about these issues.

06-00:25:18

Lage: He thought he was doing a good thing.

06-00:25:20

Longmore: Yeah, he thought he was doing a good thing, and he called me up and he said, “I’m really sorry I got into this. I didn’t know what I was getting into.” And I wasn’t very sympathetic. I said, “Well, the damage is done. You won the case.”

06-00:25:35

Lage: Yes—he did win?

06-00:25:36

Longmore: And he’s going to die. So that day, my mother had gone into the hospital the night before. She had been having intestinal problems for months. I had urged her to go see another doctor. I remember mentioning earlier in an interview that when I was a kid my parents always listened to what the doctor said, didn’t question them. Well, now things got in reverse—I wanted them to question her doctor, they didn’t, he didn’t keep track of, for a recurrence of her cancer, it had come back. The day before I did the *Today* show, she went into the hospital for exploratory surgery and cancer was all through her intestines, and I called up my dad when I got back from the *Today* show, and I said, “How’s Mom?” And he told me. “She’s not going to ever leave the hospital.” So, I mean, this was just a double whammy. The next day I went to the Huntington, and I packed up all my stuff, my Dictaphone and everything else. And people there said, “What’s going on?” And I said, “I can’t do this. I can’t do this anymore.”

06-00:26:57

Lage: Had you talked to them about the issues you were involved with?

06-00:27:01

Longmore: A little bit.

06-00:27:02

Lage: Did they have any interest?

06-00:27:03

Longmore: Some did—one woman fought with me, because she had a disabled brother and she wanted him to be able to die and then at one point she really infuriated me because she said, “Well, you can’t tell me what’s right for me.” And I— “What’s right for you, I thought it was your brother’s life we were talking about.” You know. That was the one moment when I felt really unsafe at the Huntington, otherwise it was a real refuge. Anyway, I packed myself up. I went home. I said, “I’m quitting history.” My big fear had always been if I ever really got in touch with how I felt, I would become so enraged that I would lose control and never get it back.

06-00:27:53

Lage: I mean, this kind of thing really builds the anger.

06-00:27:56

Longmore: Yeah.

06-00:27:56

Lage: And you’d already been angry.

06-00:27:58

Longmore: Yeah. So I had been just terrified of becoming too angry, because there was a lot of anger in my family. My dad was a really angry person. I had a lot of anger, and I didn’t want to give in to all that, and now I did. I just let go, and I said, “The only thing I can do, the only thing I ought to do is become a disability rights activist full-time.” So I went home and I thought, “I’m going to write a book.” So I start[ed]—

06-00:28:28

Lage: Had you burned your book by then?

06-00:28:30

Longmore: This was a year later. Yeah, and I was pretty angry about that too, because that was very painful. So I started to write and I wrote several chapters and drafted other chapters and I spent about six months doing this.

06-00:28:47

Lage: On—

06-00:28:47

Longmore: On disability rights issues.

06-00:28:49

Lage: A range of issues?

06-00:28:52

Longmore:

Yeah, and well, I'll tell you why—after six months I set the book aside. It was a torrent—it was like Niagara it came out of me. And I set it aside after six months because of something that happened that I'll tell you, but a couple of years later I went back and read it and I thought, “Whoa! You could have never published this!” [laughter] I mean, it was, it was cathartic but unpublishable. I was so angry, so—

06-00:29:24

Lage:

And did your mother die soon—

06-00:29:26

Longmore:

My mother died in December. What happened in the interim was they finally, after this doctor had said, “She'll never get out of the hospital,” my dad was a basket case, I got her out of the hospital, a week later she went home. I got my parents to let me find an oncologist for her, I called up a friend, a medical ethicist at UCLA Med. School. I said, “Leslie, I need to find the best oncologist in the Alhambra area I can.” And he found me a really good guy at the Huntington Memorial Hospital, and he took care of my mom. She went to see him, and they would come back from these doctor visits—they didn't let me go with them—and I would call them up and I'd say, “You went to the doctor today.” “Yes.” “What did he say?” And they would tell me. “Well, did you ask about this?” “No.” “Well, did you ask about that?” “No.” And then my dad would get mad, and he'd put my mother on, and she'd start crying and she'd say, “Why aren't you supportive of us?” And so I'd get really angry and then I wouldn't call for a week, and I'd feel guilty and I'd call them, and—

06-00:30:53

Lage:

Oh, terrible times.

06-00:30:54

Longmore:

And it was just, it was just, the same thing. So finally I saw the doctor myself when she was hospitalized nearing the end and he said, “I'm sorry, I can't help,” he said, “this kind of cancer is highly treatable if we catch it early enough, 80 percent success rate with colon cancer, but it's too far gone with her.” He said, “I can't give her enough chemo to fight the cancer. The chemo would kill her.” So she died in mid-December of '89. God, the week she died, I was on ABC's *Nightline*, talking about the Larry McAfee case again. I got a call, “Can you come and do the *Nightline*?” Larry McAfee by then had changed his mind. He'd decided *not* to die, and so they had me opposite the Medicaid commissioner for the state of Georgia. I'm sitting in this—it wasn't even a studio, it was an office in one of the ABC studios in East Hollywood—and they set up this camera. Forrest Sawyer was replacing Ted Koppel that night, and the Medicaid commissioner is, I guess, in Atlanta, and Forrest Sawyer is in New York, and I'm in Hollywood. And at that point—the state of Georgia, this is one of my criticisms, didn't pay for independent living. They had no independent living program, so—

06-00:32:40

Lage: And he was in a nursing home, wasn't he?

06-00:32:42

Longmore: He was forced into a nursing home and, but no nursing home in Georgia would take a ventilator user, so he ended up in the ICU [intensive care unit] in Grady Memorial Hospital in Atlanta for eight months, and then they said, "You don't belong here." Before that they had shipped him to Ohio for a while; and after that they shipped him finally to Alabama. So at this point he's still in Alabama, but he's decided he doesn't want to die. So Forrest Sawyer says to the Medicaid commissioner, "What about this, Mr. Johnson, why doesn't the state of Georgia pay for the kind of assistance that Dr. Longmore is demanding?" And Johnson says, "Well, we provide adequate care. We provide sufficient care, but we do not provide what I would call Cadillac care." So Forrest Sawyer turns to me and I went off on the guy. [laughter] I forget what I said, but I just, I really gutted him like a fish, [laughs] I mean I was so angry with that.

06-00:33:59

Lage: But were you effective, Paul?

06-00:34:01

Longmore: Oh, I think so, I mean, I was lucky, 'cause, on all these TV shows like that, they want a hero and they want a villain. And he was the bureaucrat, and I was the disabled guy, you know. And, so I got to be the hero, and of course, the host wants to associate himself with the hero. So, anyway, I did that show, and a month later, on the *CBS Evening News*, here's Larry McAfee testifying before the Georgia legislature in support of funding independent living, and he says, "If I had had that, I wouldn't have decided I wanted to die." So they funded it, and he lived for another five years.

06-00:34:51

Lage: He became, I mean, that makes him a spokesman.

06-00:34:54

Longmore: Yeah, yeah. So, but it was only experimental. It was an experiment in group living that he got to be a part of. Anyway, a couple of months goes by, in early '90 and I'm still working on this angry book, and the phone rings one day, and it's a woman from Stanford University. I had forgotten that the previous June, just before the David Rivlin case started, I had applied for a Mellon postdoc at Stanford, and I had thought, well, if I can teach at Stanford—it was a two-year fellowship—I had thought, well, if I can teach at Stanford for two years, then that would prove that I was capable, that I am capable of being a college teacher, of doing the job." Because I had applied for part-time teaching positions and I forget, maybe even full-time stuff and between '84 and then and I never got anything.

06-00:35:59

Lage: So that's part of the story that's important to note here.

06-00:36:02

Longmore: Yeah, I had not gotten anything and at one place, one school I applied to, one of the historians admitted to me that his colleagues thought I was incapable of doing the job, and I had begun to think, well, the two professors at Claremont who I mentioned in my essay who said, “No one is ever going to hire you so we don’t want to give you a fellowship,” they were right. It’s now six years after my PhD, so I had forgotten I had applied for this postdoc, and I’m thinking, well, if I can teach there for two years that would prove that I can do this. So, March of ’90, now, this is how many months later, about eight months later, I get this call from Stanford and this woman says, “I just came out of a meeting of the Mellon postdoctoral fellowship committee, and they awarded one to you.” And I said, “Good grief!” And she said, “This sounds like it might not be good news.” And I said, “Well, it’s just that I don’t do that anymore.”

06-00:37:06

Lage: You really had thought you were giving it up.

06-00:37:09

Longmore: Yeah. And she said, “Oh, well, how about if I have Professor Rakove call you.” Jack Rakove was on the committee. He’s in the History Department there. He teaches early American history. So Jack called me.

06-00:37:25

Lage: Did you know him?

06-00:37:27

Longmore: I didn’t know him then. I knew *of* him. I didn’t know him. And he said, “Well, I’m going on leave next fall and I was hoping you’d teach my course on eighteenth century America while I was gone, but it’s up to you. He said, “You know,” he said, “I wanted to get you here because I wanted somebody to talk to about early American history, but it’s your fellowship, you can do what you want with it.” So I said, “Okay, well, let me think about this.” So I got off the phone, and I said, “I’ll call you.” It was on a Friday, and I said, “I’ll call you Monday.” But I only had to think for like an hour and I said to myself, “You know, this is what you trained to do; why not just give it a shot to have that experience of teaching there and teaching early American history and just see what it’s like?” So I called him back, and I said, “Yeah, okay. I’m coming.”

This is March; I’m supposed to start teaching there in September and so I had to do a few things. I had to pack up, because I’d lived in that same apartment for thirteen years, so I had to go through all my stuff and decide what to get rid of, and meanwhile I had to start writing lectures. I reread stuff I’d read, I reread notes I had taken, I read new stuff, and I fell in love with early American history, all over again! And I wrote these lectures, and I had only done half the lectures for this course by mid-summer, and Jack calls me up and he says, “Well, I’m not going to go away after all.” And I said, “Well,

I've already prepared half the course." And he said, "Oh, well, I guess we'll have to teach it together." So I taught the first half of the course and he taught the second.

I got there, and I went to see David [M.] Kennedy who was the chair of the department, and these fellowships are for people to do research. Well, I had already published a book and a number of articles, and I felt what I really needed to do was teach full-time to demonstrate that I could do it, so I told this to David Kennedy. They only require you to teach half-time, so I said, "I want to teach a full load." David Kennedy said, "Well, that's unusual, people don't usually want to do that, but I understand your thinking, and okay, fine." So I taught a full load. So it's supposed to be two years, a year and a half goes by, and I have no nibbles for any kind of job, and I have to find a job in a place where I could live. I mean, given the climate. I couldn't live in the East or the Midwest, the climate's too hard for me, so—

06-00:40:28

Lage: Hard in terms of getting around?

06-00:40:31

Longmore: Well, in ice and snow I wouldn't be able to get around. I didn't have a wheelchair then—I couldn't walk on ice and the humidity in the South and then, in certain parts of California the smog would have been just—I mean, UC Riverside? I could never live there. A year and a half goes by, and there's nothing, nothing has opened up.

06-00:40:55

Lage: Not even to apply to.

06-00:40:57

Longmore: Not even to apply to! And, or at least anywhere I could live, and I thought, another six months and you're headed back to L.A., back to living just on SSI. Then a job opens up at San Francisco State, so I applied for it, I candidate, they made me one of the three finalists. I come here, I give a guest lecture, I get interviewed. I go back to Stanford, I get a call, "We've decided to offer the job to one of the other candidates. We wanted a colonialist, you overlap colonial and revolutionary, she's strictly colonial." "Okay, I understand that." I'm crestfallen. A week goes by, I get a call back. "She turned us down; if you're still interested, the job is yours." Yeah!!! [laughter]

10-00:41:44

Lage: Wow! I think we should end right there today.

06-00:41:51

Longmore: Okay. Sure.

06-00:41:51

Lage: Is that, or do you have a thought you—

06-00:41:55

Longmore: Well, I can tell you one other thought. I got to San Francisco State. I actually spent a third year at Stanford.

06-00:42:02

Lage: Oh, you did.

06-00:42:04

Longmore: Yeah, yeah. Somebody turned them down on a Mellon postdoc, and so David Kennedy said, "It's yours if you want another year." And there were people there who wanted me to stay, but that didn't work out, and I actually think, in the long run for me, it's better, because I really, the longer I'm at San Francisco State, the more I realize it's the ideal place for me. Anyway, this is now 1993. I had started my PhD in '71 and never had a tenure-track job. I was forty-six years old. I get to San Francisco State, and I moved in here, and I moved here because I wanted to be able to walk to campus, and I'm not kidding—the first year, virtually every single time I went over there, I would cross Holloway Avenue and set foot on the campus and I wouldn't get ten feet onto the campus without stopping and saying to myself, "You are a professor at this university!" I was just astounded, you know. So let's end there.

06-00:43:20

Lage: Okay. That's fabulous. [laughs]

[Interview 4: October 25, 2006]

[Audiofile 7]

07-00:00:00

Lage: Today's October 25, 2006. This is our fourth interview session. We're on tape seven and we're moving along very well, aren't we? I wanted, if you don't mind, to just pick up from last time. This is not what I wrote to you that we would start with.

07-00:00:18

Longmore: Okay. I forget where we ended.

07-00:00:20

Lage: We ended with your arriving on this campus and your feelings about it.

07-00:00:23

Longmore: Oh, yeah.

07-00:00:24

Lage: But we skipped over Stanford, but we also—I was thinking about what you'd talked about of the disability rights community in Los Angeles, and I would hope that you would reflect some on your sense of whether you felt a member of a community there, or whether you had a growing sense of identity as a person with a disability. Would there be more to say about that?

07-00:00:51

Longmore: Sure, yeah. Well, very definitely what happened in the early eighties and all through the eighties was that I became more and more involved in the L.A. disability rights activist community and did feel like I belonged.

07-00:01:09

Lage: Yes. You've mentioned, in your church community, this feeling more and less a member, and I wondered—

07-00:01:17

Longmore: By the early eighties, I exited church altogether. I—

07-00:01:26

Lage: What did you find there that made it feel like a community, find in the disability group?

07-00:01:32

Longmore: Well, it's actually similar to the religious community I had been a part of for my whole life up to that point. A common cause, a common perspective on the world, shared set of values, collective identity, except that rather than it being all inherited we were making it as we went along. We were figuring it out. We were figuring out what exactly is the message we want to put out to the world, to the larger society. What's our own understanding of all these things? We were formulating that as we went along, we were trying to—

07-00:02:16

Lage: This was something that was talked about in—

07-00:02:19

Longmore: Yeah, we were discussing what disability is. We were formulating a minority group analysis; we did explicitly talk about disability as a kind of minority status, and that's where my connection with the activist community was also extended into the academic sphere. I mean, that's what Harlan Hahn, and Carol Gill, and I were doing at USC, and we were in touch with other disabled scholars, disabled intellectuals, disability rights advocates who were in that community.

07-00:02:57

Lage: Were the advocates that you were in touch with, like say, June Kailes or Doug Martin, who weren't, I assume, part of this academic community at USC—

07-00:03:07

Longmore: Well, Doug was, Doug was an intellectual. I mean, Doug had a lot of serious intellectual interests, so he was working on public policies, but Doug and I became very close friends, and we talked about all kinds of stuff.

07-00:03:25

Lage: It sounds like there's a lot of interaction.

07-00:03:27

Longmore: Yeah, there was, there was. I mean, some of these people are really, really smart people, and we spent a great deal of time—I mean, Carol's husband Larry was a special education teacher in the San Fernando Valley --

07-00:03:40

Lage: What was his disability?

07-00:03:41

Longmore: He had polio, but he worked with kids with emotional disabilities. It's really interesting. All the people with disabilities, who end up in a career where they work with people with disabilities but it's a different kind of disability than their own.

07-00:03:59

Lage: Yes.

07-00:04:01

Longmore: Anyway, Larry, and Carol, and I became very close and were involved with other people like Barbara Waxman, and we spent a lot of time thinking through—well, I told you about Carol and I at USC, we spent a whole year with our own kind of two-person disability studies grad seminar.

07-00:04:21

Lage: I remember that, but I was kind of thinking internally what were you going through, and then personally, the community, the identity.

07-00:04:28

Longmore:

Well, it started already, before this, when I got, in the late seventies, got involved with the Polio Survivors Association, but it accelerated in the early eighties and on through the eighties, because I was in touch with people who had similar experiences to my own. Some of them had similar experiences in getting their education, virtually all of us had physical disabilities. The Deaf community had, there was an activist Deaf community in L.A., and I got to know people there as time went on, but they really maintain a separate community. I had some contact with blind leaders there, and I spoke to the California Council of the Blind at a meeting of theirs at one point in L.A.

07-00:05:26

Lage:

Were the viewpoints similar there?

07-00:05:28

Longmore:

Yeah, yeah, but the people I was most involved with were people who were physically disabled activists, a number of them like Doug and Jim, Carol, Larry, Barbara were all involved in the Westside Center for Independent Living, so I was involved with people whose disability experiences were rather similar to my own. Carol and Larry had both had polio, Doug had polio, a number of other people, and one of the immediate and also deepening insights I got from these contacts was that a lot of stuff I had thought had been peculiar to me, personal, internal, was actually common and social. I mean social in the sense that it wasn't something that *we* had generated—it came from society into us, so that was a key thing. The other thing, I think I may have said this before to you, the other thing I began to realize, and this is in the early eighties, was by having these contacts with people who were very political about disability and caused me to be political in a much deeper way than I had ever been, I realized that the prejudice and the discrimination, the oppression were much deeper, much fiercer than I had acknowledged or recognized. Two examples—when a bunch of us got involved with the Elizabeth Bouvia assisted suicide case, that was a moment when I really got much more deeply in touch with the depth of the prejudice against people with disabilities.

07-00:07:26

Lage:

Yes. We, we did talk about that.

07-00:07:28

Longmore:

Yeah. Another moment in the early eighties I was talking to a friend and I said, "I'm realizing," and I said this to you too before, I think, "This problem goes a lot deeper than I ever thought, and it's not going to be solved in my lifetime, and if this is just, if dealing with disability, were just a matter of my personal adjustment and coping, I can do that, but if it's this deeply historical and social and cultural and political, it's going to take a very long time. It won't be in my lifetime, and I don't know if I want to face that reality." But I did, and I could because I had this community I had become a part of.

07-00:08:12

Lage: Yes, you had said that before and I wondered how that followed through--

07-00:08:18

Longmore: And there were also cross-disability connections. When I did my book burning, that was '88, not all that long before I left L.A., October of '88, at that demonstration there were people from the Deaf community, the leader of the basic Deaf organization. There were people from the blind community. Some people came down from the independent living center in Santa Barbara and people from all over L.A., so it was a cross-disability protest demonstration.

07-00:08:55

Lage: Were there very many people, racial minorities involved in the disability community then?

07-00:09:01

Longmore: No. As with disability rights advocacy in most places most of the time, it was white and middle class.

07-00:09:09

Lage: Do you have a sense of why that was—or is?

07-00:09:13

Longmore: I think that there were a lot of issues that complicated things for people of color with disabilities that white suburban activists really didn't understand. There were also not very many people, white people, who were of low-income backgrounds, not many poor, white, disabled people.

07-00:09:40

Lage: Who got involved.

07-00:09:41

Longmore: Right. A lot of us had become impoverished as adults because of the way the system works, but that's not the same thing as being a poor person, you know. I mean, I lived the first half of my adult life on benefits exclusively, and I experienced, in a sense, what it's like to be poor, but I didn't have—I mean, well, one of the things that made it so hard was that I had come from this suburban white middle-class background and now I'm thrust into a different stratum of society, that I really, apart from disability, I wouldn't have experienced.

07-00:10:29

Lage: Right. It's sort of what you were saying about the gender issue. You had a sense of entitlement as a middle-class American.

07-00:10:35

Longmore: Yes, yeah, yeah.

07-00:10:37

Lage: That maybe—

07-00:10:38

Longmore: The white middle-class male.

07-00:10:39

Lage: Yes.

07-00:10:40

Longmore: Well educated, yeah, yeah, exactly.

07-00:10:43

Lage: Interesting.

07-00:10:44

Longmore: There also at the same time there were very few, if any, people who were really affluent, wealthy. I mean, I met a few people, but that was through some of the Hollywood-related advocacy work that I did with the Media Access Office in the eighties.

07-00:11:01

Lage: Has that changed over time? Has there been more reaching out to people of color, or—

07-00:11:08

Longmore: There's, there's—yeah, there's more. I mean, Lilibeth Navarro went to work at USC. She's a Filipino American. She went to work at USC for our program there for a while. She was a student at USC. There were a few other people in L.A. in the eighties. I think there are more people of color in a lot of places, I mean regionally and certainly in California, than there were twenty years ago, but it's still predominantly a middle class and white movement.

07-00:11:47

Lage: Were there any fault lines back in those days—we might have changes over time—but fault lines between the type of physical disability, or the time of onset, whether you were born disabled?

07-00:12:02

Longmore: Yes, yes, yes, all those, all those factors. Age of onset, were you born with it, did you grow up with it, did you acquire your disability as an adult?

07-00:12:10

Lage: Now how did that figure into people's attitudes? Or in people's embodiment—

07-00:12:14

Longmore: Well, it's really interesting in terms of the hierarchy of stigma that society creates, the earlier you became disabled, the more stigmatized you are. The longer you are normal the more valid or the less invalid, I should say, you are. But within the disability rights movement, it was the reverse, ultimately. It's maybe more complicated than I'm going to make it sound right now, but I can remember an occasion when a woman I met who had been in an auto accident in her late twenties and sustained a spinal cord injury that caused her to have

difficulty walking. Sometimes she used a wheelchair, a manual chair, mostly she walked. She was doing some work with disabled women in L.A. and she told me that she didn't feel like she was legit, that these other women were the legit ones because they had all gotten their disabilities as children or had been born with them, and I said to her, "There's no more legitimate and less legitimate; we all have different kinds of disability experiences." But she felt like these were the true, the authentic disabled people.

Another thing that happened in that era was some of the activists involved in independent living and deinstitutionalization for a time came to regard people who had been in institutions, grown up in institutions, gotten out at some point in adulthood—they're the really disabled people, in the sense of authentic, you know. And [chuckling] I really had trouble with that. I said, "Wait a second. How is so and so more authentically disabled than you and I? If it hadn't been for what you and I have done, in terms of advocacy, that person would still be in an institution, you know?" I mean, I—there are just different kinds of disability experiences, just varieties of experience, and they have their own validity. This kind of, this kind of measuring and rating of disability experiences as more or less valid, well, it has its parallels in other minority groups, but it's all so detrimental to us working together and it just doesn't pay attention to the realities of our experiences.

07-00:14:48

Lage:

Well, I ran across, and I can't remember where—it might have been in her oral history—Judy Heumann referring to you as a born-again disabled person.

07-00:14:58

Longmore:

Yeah. Well, that has to do with the stage in my life at which I got involved politically. Judy had been involved politically from a younger age.

07-00:15:12

Lage:

Right. She seemed to have been born with this [activism].

07-00:15:15

Longmore:

Yeah. I'm not sure that's true, but it was earlier on. And that's another kind of measuring of people's validity, in this case, political validity, that I don't think serves us well. Harlan Hahn used to say that from a political organizing standpoint, we're doing something that's extremely difficult to pull off. We're asking people to identify with the most stigmatized element of their identities. And that's an awful lot to ask people, and we were doing it at a time when there wasn't a whole lot of positive advantage in doing that. Things have changed somewhat in the twenty-five years since I got involved in the disability community in L.A., but when I was in college, on the one hand I was thinking about prejudice and discrimination, on the other hand I didn't want to be identified with those other visibly disabled people there; I was trying to get social acceptance. When I got to USC, I don't know if I told you this before—one day I was walking across the campus and here comes an undergraduate student, a guy riding a sports wheelchair, and as you pass

people, you might acknowledge them with some kind of eye contact, nod your head. When we got to that point, that distance between us, as we approached one another, he looked away from me. He didn't want to make eye contact. And at first, I was annoyed, I was angry at him for doing that, and then the more mature, wiser, more understanding empathetic part of me said, "Well, Paul, you used to do exactly the same kind of thing when you were his age, and do you remember what it felt like? It took you a long time to realize how lonely and isolated you felt because of that. And here's a guy who doesn't want to be publicly connected to you by making eye contact and acknowledging you, but what that really means is there's a deep part of himself that he's trying to avoid identifying with. So it's probably pretty hard for him here. Who does he have to talk with about all this stuff? Do you remember the experiences you went through at his age trying to figure this stuff out and how hard it was, because there was nobody you were willing, or maybe able to talk to?"

07-00:18:18

Lage: Yes. Did you ever get him involved in any of the disability studies programs?

07-00:18:22

Longmore: I never met him. I never—

07-00:18:23

Lage: —never saw him.

07-00:18:23

Longmore: And that was the only time I ever saw him. My experience at schools like USC and Stanford is that the kind of person with a disability, whether a student or a faculty member, the kind of person with a disability who ends up at a private more elite college or university is the kind of disabled person who has the hardest time identifying with other people with disabilities and with themselves, with those aspects of themselves.

I experienced that definitely when I was at Stanford. There were about 160 or 170 students with disabilities who were getting services from the Disability Resource Center at Stanford, but there were only a couple dozen who hung out at the Disability Resource Center. And of those, maybe half were really interested in exploring the possibility of community. And these were kids with a variety of disabilities who had never had a disabled friend growing up, and they had been schooled to be overcomers. They get to Stanford, and for the first time because of the DRC they got to know one another. I think what happened was they started to compare notes, found out as I had found out in the L.A. disability community, that there are all these experiences I share with people whose disabilities are actually rather different from mine, maybe very different—I mean one guy was deaf, there were a couple of blind students, there was a young woman with cerebral palsy who drove a scooter, there was a guy who had been born without hands, so the disabilities were very different, but these kids started to form a community among themselves, and I

got there and I wanted them to be, or become political activists. Did I tell you this already?

07-00:20:33

Lage: No, but that's our next topic—Stanford, so let's go on with it.

07-00:20:37

Longmore: Well, I got there and they really taught me an important lesson. I was very disappointed in them at first because they weren't political, and I started to talk to them in rather activist terms and most of them, I scared the hell out of. I mean, they really got a little frightened of me, and after that first quarter I said to myself, "You need to back off a little bit and just get to know them, and you need to understand the route they're taking. They're not ready to be political about this. What's really important to them is they have people they can be friends with who are disabled." They had organized what they called a speaker's bureau. They would put on panels in dorms to try to educate nondisabled students in the dorms about disabilities.

07-00:21:33

Lage: Well, there's some politics involved in that.

07-00:21:36

Longmore: Well, frankly their politics was really undeveloped and from my perspective had a long, long way to go.

07-00:21:44

Lage: I see, the things that they would emphasize?

07-00:21:46

Longmore: It was mostly attitude change, thought, it wasn't really very political. They didn't know the politics, you know? But that's where they were at, and it took me a while to accept that and to say what they really need is the community of one another, and you need to be patient and let them develop at their own pace. What eventually happened was, by the end of the first year, the seniors among them said to me, "Are you going to teach a course on disability history or disability studies while you're here?" Because I was supposed to be there for two years, ended up staying for three. And I said, "Well, I wasn't going to do it until next year, maybe." And they said, "Well, we're all graduating in June. If you don't teach it in the spring quarter, we won't be able to take the class." So there were about six of them. So I said, "Okay." So I arranged to teach it, and they recruited some other people, and I had about ten students. All of those the courses at Stanford are colloquia, a seminar type of class. But I had ten students, and that was the first time I taught the course there, and then I taught it twice more, each of the next two years.

07-00:23:07

Lage: Each year.

07-00:23:08

Longmore: And each time I had more students and then the last time I taught it everybody knew I was leaving to come to San Francisco State, so I had twenty-four students, which is really big for a colloquium.

07-00:23:19

Lage: And were there any non-disabled students?

07-00:23:23

Longmore: Yes, at least a third of each class was students with disabilities. In the last course, the one with a couple dozen, about a third had disabilities and two-thirds did not. The really interesting thing about that class was there were—it was like Noah's ark in one sense—there were two of every kind. There were a couple of kids with a certain kind of disability, a couple of other kids with another kind of disability, and there were a couple of Latino students, a couple of African American students, a couple of lesbian students, a couple of Asian American students. It was a really interesting and valuable mix, and these other students, I think, virtually all the students of color were not disabled. These other students all had some connection to people with disabilities.

07-00:24:26

Lage: Oh, they did.

07-00:24:27

Longmore: Either because of their experience at Stanford or within their own families. That was true with the other non-disabled students the previous two years. One of the things that happened in that class was, I was trying to present a minority view perspective on disability and for the students with disabilities this was a new idea. They weren't quite sure it was a legitimate idea, but the students of color, in particular, all immediately saw the parallels.

07-00:25:04

Lage: Hmm!

07-00:25:05

Longmore: So they were the ones who essentially took what I said to everybody, and they said, in effect, to the disabled students, "That's right. You belong to a minority group." And the students with disabilities felt legitimated then in doing a minority group analysis of disability in their experience and looking at prejudice and discrimination that way.

07-00:25:32

Lage: It's interesting that the students got it so well, but maybe you found later some of the scholars of race and ethnicity didn't embrace that idea.

07-00:25:45

Longmore: Well, they're of an older generation. I think that might have something to do with it, but that's been changing too, I think, gradually. In fact, there's a project at Cornell University on the future of minority studies that was

launched by scholars of color from several minority communities, and they've included a couple of white scholars with disabilities in that project.

A similar thing to that class happened in one of the dorm panels that the students did. It was in the African American theme dorm, and I happened to attend this one, and here were these students, black students in the audience, and most of the kids on the panel are white and have disabilities of various kinds. They do their presentations and it wasn't all that political, but it had gotten to be more so than it had been in past quarters, and they finished and they want audience interaction, and some of these black kids are saying to them, "Wow, I never realized it before, but being disabled in this culture is belonging to a minority group." And I could see that these kids with disabilities on the panel felt validated in ways they had not before. So that was a really interesting experience with those students.

I'll give you one example from the class, that last class I taught. I had the students, each time I taught the class, read Irv Zola's memoir, *Missing Pieces*, which is about his experience of going to Het Dorp, a community in the Netherlands that was built and designed *for* people with disabilities, mostly physical disabilities. There are some questions about this. I mean, in a way it's segregation, in another way it's a chance to form community, and Irv wanted to go there and do a kind of participant observer study. It had a profound impact on him, that he reports in that book; it really made him see himself differently. Irv had polio, and I mentioned it earlier, he's regarded as the father of disability studies in the U.S., and he did this trip before there was any disability studies at all in the U.S.

07-00:28:39

Lage:

In the seventies?

07-00:28:40

Longmore:

In the late seventies, yeah. Anyway, he tells a story at the end of the book of flying back to the U.S., back to Boston, and he says that always in the past when he would get on a plane, he would leave his leg braces on, but it was very uncomfortable, but he would leave them on because he didn't want people to see his leg braces. The leg braces were underneath his pants, but it was very uncomfortable. And this time he decided he wanted to be comfortable on the flight, so he took the leg braces off. And so the leg braces, they got stowed in an overhead compartment, but his legs were exposed then. He said he was uneasy about doing this, but he did it. So I said to the class, "Why do you think he was uneasy about doing that?" And various students gave me answers, and I don't usually respond to students this way, but with each answer, I said, "No, that's not it. No, that's not the reason."

People were getting a little exasperated with me, so I said, again, "Why did he not want anybody to see him with his leg braces off?" And a girl who rode a wheelchair was looking down at the table in front of her. She didn't look up,

and she said, “He didn’t want people to see his legs.” And I said, “He didn’t want people to see his withered, shriveled legs, because he felt ashamed of them.” And you could have heard a pin drop. There was a woman in her mid-forties who was in the class, and she had had a spinal cord injury about ten years earlier and had come back to school now. Later on, I think the next day, I saw her, and she said to me, “You know, when you said that about Irv’s Zola’s legs, it suddenly dawned on me that for the last ten years, I have constantly kept my legs covered, and I realized I didn’t want anybody to see them, because I felt so ashamed.”

So, well, I’m not sure where that’s going, but—

07-00:31:19

Lage: Well, the awareness that was being developed—that you saw the changes, the shifts.

07-00:31:23

Longmore: Yeah, well, I guess the point is that I had gone through an experience similar to that, of those students in the class, some years earlier. It’s just, when I was an undergraduate I was ashamed, and I dressed up very fashionably. You wouldn’t know it now, [laughter] but I did, I really spent a lot of money on clothes, and I thought I was passing, and I thought I looked like everybody else, and it was always a jolt to me when I would see how different I looked. Sometime during the eighties, probably because of being a part of the L.A. disability community, I began to come to—I began to address that sense of shame about my body, and began to come to terms with it and become more accepting. That’s a very hard thing to do in a culture that’s so stigmatizing.

07-00:32:24

Lage: Right there in the heart of Hollywood.

07-00:32:26

Longmore: Exactly, southern California with its—well, anywhere in California with its emphasis on appearance, yeah. I’ll tell you one other experience I had, and it’s again—I think because of being part of the L.A. disability rights community—it’s again a realization of how much I had screened out. I was doing research at the Huntington Library, and one day, somebody else there—I always thought of the Huntington as a kind of refuge for me. It’s just such a wonderful place to do historical research and I kind of realized that it felt like a place where I was safe. Two experiences happened—one involving a woman making a remark about assisted suicide, in favor of it—

07-00:33:17

Lage: And her brother.

07-00:33:18

Longmore: Yeah, and her brother. But this was another moment. I forget what the person said to me, but this woman said something to me that was really condescending and biased. And it really jolted me, but the really significant

thing was, I said to myself, “That can’t be the first time somebody has said something like that to you. This has to have been happening a lot. All your life, or most of your life. How come you didn’t notice it? You have to have been screening this out. It had to have been there, and you just disattended to it, you ignored it, you made yourself oblivious to it in order to get through, in order to survive psychologically and morally.”

07-00:34:21

Lage: It sounds as if that was also what your mother encouraged. “Oh, Paul, that’s not true”—

07-00:34:28

Longmore: Well, I think my parents knew that the prejudice was there, and they didn’t know how to deal with it. It frightened them and so better to pretend that it’s not real.

07-00:34:39

Lage: Right.

07-00:34:39

Longmore: Yeah, and I think that’s why when I became an activist and very political about this stuff, that was scary for them too. Hey, it was scary for me! [laughs]

07-00:34:53

Lage: [chuckling] But if you hadn’t become an activist how would you have handled all this knowledge?

07-00:35:02

Longmore: Well, I probably, I would have continued to stay away from disability-related stuff. I mean, I could have had a—there are a lot of people in academia who have very successful careers and who have disabilities. They’re real strivers. There are a lot of senior scholars, well, fewer now, because we’re getting a lot older, but a lot of people who had polio, who became very major figures in their field, so I could have done that.

07-00:35:37

Lage: And didn’t address—

07-00:35:38

Longmore: Well, they never addressed disability issues, and in fact, that was one of the things Irv Zola discovered at Brandeis, and he came to the point where he started to address his own disability-related needs for accommodation and access, and for the longest time for many of us it wasn’t a matter of a right—you have a right to these accommodations—it’s a matter of, it’s your problem, you work it out. I mean, I went through school at a time when, at least at the schools I went to and most other schools, there were no disabled student services offered.

07-00:36:16

Lage: Now what about, I was thinking now about Stanford. You mentioned that there was a Disability Resources Center. You got involved with it; how did you happen to get involved, in what ways?

07-00:36:31

Longmore: Well, when I got there I went over there and introduced myself and met a lot of people and they knew I was coming. They knew I was going to be there for a couple of years, and some of the students had wanted to meet me. The guy who had directed the DRC was a friend of mine, and I was very disappointed—he left almost, well, just as I got there he moved to another job. I started to hang out with the students. For a time I had a group of the guys coming over to my apartment for pizza occasionally, so we could just hang out and talk to one another. As I said, they took my class, I went to some of these dorm speaker's bureaus.

07-00:37:29

Lage: How were the accommodations at Stanford? And the access.

07-00:37:32

Longmore: Well, they had, they had a golf cart, and they had a lift-equipped van that was available most of the time, but I was also walking a lot more strenuously in those days. It was a mile and a tenth from my apartment on campus to the history department, and I would walk one way. I would get a ride back, but I—

07-00:38:02

Lage: Was this because you thought it was good for you? Or—

07-00:38:04

Longmore: I liked walking, and I yeah, I thought it was good for me. I was also wearing myself out, I'm sure. I didn't really ask for much in the way of accommodations. It wasn't until I got to San Francisco State that I thought more fully about what kind of accommodations I needed to do my job, and this is a good example of how even somebody who's an activist can have rather limited knowledge of what they need or what's possible. The person who was the ADA compliance officer at state, Kirk MacGugan, who has now passed on, when I first got here said to me, "What kind of accommodations do you need?" And I said, "Well, I need a speaker phone in the office." And she said, "Well, what else?" I said, "That's it."

She said, "How," she had met me, you know—she had polio too by the way--she said, "So how do you get into your office or your apartment?" And I said, "Well, what do you mean?" "How do you unlock the door?" I said, "I don't, I can't unlock the door. I have to have somebody unlock it for me. I can't handle a key, I can't get it into the lock." She said, "Well, what if we got you a mechanical or electronic key pad for your door lock and then a lever handle on the door?" And I said, "Oh! Yeah, I could do that." So my office on

campus was the first time in my life that I could unlock a door unassisted, and I had never thought of that before. I wasn't aware of it.

07-00:39:56

Lage: Well, is this partly the impact of the ADA and better programs, or—

07-00:40:02

Longmore: That, plus, one of the thrusts of the whole disability rights movement has been access to information. What's out there, what's available, what kinds of not just devices, but services, might be available to you so that you could do things that you want to be able to do. So that you can make choices and, I mean, I didn't have the information.

07-00:40:34

Lage: Yeah, right, crazy. Well, is there more about Stanford? You said you deliberately taught a great deal. How did, how did that work and how did you find your endurance and your teaching experience?

07-00:40:47

Longmore: Oh, it was fine. Well, you know there was teaching there, and there was teaching here. It's a heavier teaching load here, by far, and I taught what was a full load there, which would be about a half load here. And I got really good teaching evaluations. At one point the chair of the History Department came to me and said, "I just wanted you to know that on the student evaluations, you got the highest scores this last quarter of anybody in the History Department." So I thought, "Well, that'll help." And I think it did in getting this job here. [loud humming noise in background]—Is that going to interfere?

07-00:41:30

Lage: I think it will. Can I close this window?

07-00:41:32

Longmore: Yeah, yeah, sure. It's going to get hot.

07-00:41:33

Lage: Yeah, well, maybe not for this brief time. [closing window]

07-00:41:50

Longmore: Okay. There was no problem with my physical energy, I mean teaching at Stanford it's easy. They're mostly, as I said, colloquia. You have small groups of students, they're very highly motivated, they do all the work for you, so, you assign a book a week, they read it, they talk.

07-00:42:15

Lage: Yes. [chuckling]

07-00:42:16

Longmore: You interact. It's not hard.

07-00:42:18

Lage: And you taught colonial history?

07-00:42:20

Longmore: I taught all kinds of things. I taught initially a course on American colonial history. I taught a course on American religious history. I taught a disability studies course. I taught a seminar on oral history methods and had students do projects, research frameworks using oral history. Yeah, those were the four courses I taught. What else did I teach? I taught something else, but I can't think of what it was now. I forget.

So I taught a variety of things and then I got here, and my concern had always been that, well, if I get sick, if I get a cold, a respiratory infection of some kind, I have to be very careful. I have to basically go to bed. Even though I don't feel that sick, I have to go to bed and just lie still until I'm over it, because my body just has to use all its resources to fight that thing off, so I just have to rest until I'm over it. So I thought, "What if I get sick in the middle of a semester? What am I going to do?" 'Cause it could take two weeks of just lying down and not doing any work—how would I go to lectures? The amazing thing was, the first decade I taught here, it never happened! I never got sick! It may have been partly because I was eating better than I had, I was doing some nutritional supplements, that might have helped I don't know—I used to get sick a lot more often in L.A.

07-00:44:16

Lage: Hmm. Maybe the smog.

07-00:44:17

Longmore: Maybe it had to do with the smog. And then when it finally did happen, it happened right at the end of a semester. The last two weeks. I didn't get to the American Revolution that year. And I didn't know it at the time, but it scared the hell out of the students in my class. They really worried. And when I came back in the fall, a couple of them came up to me and said, "You know, we were really worried about you." And I said, "Oh, I'm sorry. I didn't want you to worry. I mean it wasn't like my life was in danger, I just have to be really careful when I get sick." But it kind of it was a detriment to that particular course.

07-00:45:06

Lage: Yeah, yeah. Now, you've said that this campus has been a very good place for you.

07-00:45:12

Longmore: Yes.

07-00:45:12

Lage: You said that right towards the end of our last session. Why has it been such a good place?

07-00:45:15

Longmore: Well, in a number of ways. For one thing, San Francisco State—we got sued a number of years ago, by a group of *my* students. I did not put them up to it. They sued over access issues.

07-00:45:35

Lage: Were you involved at all?

07-00:45:37

Longmore: I'm on the board of directors of Disability Rights Advocates that sued this university on behalf of the students. I felt caught in the middle. I really felt embarrassed. This is my university. I wanted to talk to the president of the university. I went to the university's legal counsel, and I walked into her office and I said, "The first thing I have to tell you is I'm on the board of directors of Disability Rights Advocates." She said, "I can't talk to you." So then I talked to the executive director of DRA, and he said, "Stay out of this." And I said, "Well, I feel like I'm caught in the middle." And he said, "Stay out of it."

So I stayed out of it, and there was eventually a settlement. The result of the settlement was the university hired a fellow named Gene Chelberg [spells]. And we created a new position. We combined the directorship of the disabled students services program with all the compliance and access issues, all the compliance issues around access and accommodations for faculty and staff and from the physical layout of the university. It's all in one job now. It's called the Disability Programs and Resource Center.

At that point, which is now, what—four years ago, I guess? We were one of just a couple of universities in the country that had done this. That administratively took all those different responsibilities and put them in one place, and we hired Gene to do it. I ended up being the chair of the search committee for that position, and I had known Gene since he was an undergraduate at the University of Minnesota, Minneapolis, so I tried to maintain a neutral position, and he sold himself. He's one of the leading people in the country both on services to students with disabilities and on access issues. So he's been working with people all through the university, and our campus is becoming, it's well on its way to being, one of the most accessible, physically accommodating campuses in the country. And I think the accommodations for faculty and staff with disabilities have improved a great deal, as well.

07-00:48:14

Lage: Now, what position did Kirk MacGugan have?

07-00:48:17

Longmore: She was the ADA 504 compliance officer, that's one of the positions that got—

07-00:48:24

Lage: A faculty member?

07-00:48:23

Longmore: Well, she was also a faculty member in history. There was a separate person who was head of the Disability Resource Center. That was only services to students with disabilities, so those two jobs got joined together under—

07-00:48:42

Lage: So you think that's a good arrangement?

07-00:48:43

Longmore: Oh, yeah, I think administratively it works really well. It makes a lot more sense. So everything non-academic related to disability is under Gene's assignment. So that's one reason I'm really at home at San Francisco State because it's a university that has been changing itself, and part of what that means is that because of the work of Gene, of me, of Anita Silvers, a philosophy professor here with a disability who's been here for a very long time, and some other people, San Francisco State, which has a very strong sense of itself as committed to democratic diversity has been including people with disabilities in that notion of what diversity means.

07-00:49:43

Lage: When you first came did you have a sense of that as well?

07-00:49:47

Longmore: It was on its way in that direction. The History Department said, "We're looking for a colonialist, American colonial history." I said, "I also do this other thing—disability history." They said, "That would be really good too; that would be a real asset." Now that's not the reaction I had ever gotten before.

07-00:50:09

Lage: Yes. What about Kirk? What did she teach?

07-00:50:12

Longmore: Kirk taught a course on disability in America before I got here. Kirk died not too long after I got here. She had cancer. The History Department did not seem at all nervous, at least as far as I could tell, about my being able to do the job. That had been an issue before when I had interviewed. I think the time at Stanford helped to demonstrate that I certainly could do the work. Kirk already had taught in the department and Anita Silvers in philosophy, they all knew her. The interesting thing was, they hired me and a couple of years later the chair of the History Department said, "You know, there are people in the administration who are taking credit for you as an affirmative action hire." And I said, "Well, there is no affirmative action for people with disabilities." [chuckling] So, but that signaled a change too, I mean, that they *wanted* to take credit for it, that they regarded a disabled faculty member as an asset.

This larger commitment to diversity and the fact of diversity at San Francisco State is another reason I've really come more and more to feel at home. The first thing that strikes you is the ethnic and racial variety, but it's not too long before you realize that there are all kinds of other diversities as well. There are a lot of immigrant students, a lot of international students, there's a big range in terms of class. Very many students are the first members of their families to go to college. A lot of people from working-class backgrounds, but a lot of middle-class suburban kids as well, um—

07-00:52:23

Lage: What about older students?

07-00:52:25

Longmore: There are a lot of students in their thirties and forties. I've had students in their fifties. They come back to get an advanced degree. We're really good with master's programs. We've got a lot of very valuable master's programs, and a lot of people come back who are older, but there are undergraduates too. One of my favorite students, one of the students I'm proudest of is a guy who started out at the University of Connecticut at the classical age to enroll as an undergraduate, and he wasn't ready. He didn't want to be in school and he dropped out and he worked for about ten years, and then he was about twenty-eight, comes out here, enrolls in San Francisco State in history. Now he's ready, and he really wants to develop himself as a scholar, as a historian. This guy was not the most talented person I ever had as a student, but boy, he worked hard and I really admired him for that. He stayed on and got a master's, and he really kept trying to stretch himself. He has now finished his PhD, elsewhere, of course. We get students, like that, you know. I mean, it's a university that provides second chances for a lot of people, so I appreciate that kind of diversity as well.

There's a sense of this university as being a—well, it aspires to be the leading public urban university in the country, and I think you could make a good case for that. It's certainly one of the best. I was on the strategic planning commission several years ago, and I got to know people from throughout the university, and I realized there are lots of people in the faculty and the administration who are idealists. They have a real vision and a sense of mission of San Francisco State as serving the kinds of students we serve and being located where we are as a public urban university committed to students who have maybe not gotten very many institutional opportunities, so it's a really civic-minded, very democratic vision of what this university ought to be like.

07-00:54:47

Lage: It sounds like a lot of institutional commitment, which you don't—

07-00:54:51

Longmore: Very definitely.

07-00:54:51

Lage: —find as much as you once did, I think, at Berkeley.

07-00:54:55

Longmore: It's very strongly committed to, from the top all the way down—and it doesn't just come from the top down, it's everywhere.

07-00:55:07

Lage: But I mean the faculty committed to the institution, and the administration.

07-00:55:10

Longmore: The faculty and the administration, yeah, yeah. No, very definitely. One of the things I was told when I got here was faculty tend to leave soon or stay forever. And I could see that. A lot of my colleagues have been teaching here for thirty years.

07-00:55:24

Lage: I have heard a lot of complaints about teaching load.

07-00:55:27

Longmore: Well, it's heavy. In most departments it's four courses each semester. In History, it's three courses each semester.

07-00:55:35

Lage: So History—it's not as heavy.

07-00:55:37

Longmore: Well, we negotiated course reductions to do research. How you're supposed to do research and publish books with a one-course reduction, I'm not sure, but because of the Institute on Disability, which I direct, I've been able to buy out more of my time.

07-00:55:52

Lage: And that's—you get sort of credit for—

07-00:55:55

Longmore: Well, yeah, the budget of the institute pays for course reductions for me, so I ended up teaching, I've got a course load that's better than Berkeley, you know.

07-00:56:10

Lage: Yes. A couple of courses a—

07-00:56:11

Longmore: Oh, I teach three a year.

07-00:56:13

Lage: Three a year! That's very good.

07-00:56:15

Longmore: Yeah, yeah! That's better than it was at Stanford!

07-00:56:18

Lage: And how big are the courses?

07-00:56:20

Longmore: Well, students shy away from American colonial history, because they think it's about, you know, pilgrims and things like that, and they think it's going to be really boring, so the enrollments are not as big as they might be in another class, but I get twenty-five to thirty usually. It also depends on what time of day you teach, because a lot of our students are—they're all commuters, virtually. A lot of them are working, they've got families, so they come at the time when it's most convenient for their other needs. A seminar—grad seminar, a good size is fifteen.

07-00:57:05

Lage: How much teaching do you do in disability issues?

07-00:57:09

Longmore: I've taught my course on disability history a number of times. I'm not sure what's happened—in recent years I've had trouble making the enrollments. At Stanford it was easier to get enrollments and at USC too, because you had a lot more students in residence living on campus. Here it's a commuter school, and students tend not to be terribly aware of what's going on outside of the department where they're studying, so they don't have a lot of contact with one another. You can see them—they sit there in your classroom and a lot of them don't know one another. They come to class, they take the class, they leave. They don't develop friendships or relationships as much as you would, say, at a residential college or university.

07-00:58:01

Lage: It looks like you have students living in this building.

07-00:58:04

Longmore: Oh, there are a lot of them, yeah. This is not university property. Yeah, there are—more than one.

07-00:58:09

Lage: What about—

07-00:58:12

Longmore: You've got a flashing light—is that—

07-00:58:13

Lage: Oh, yeah, well we have two minutes. Why don't we just stop here and change our tape, thank you.

[Audiofile 8]

08-00:00:00

Lage: Are you okay as far as—

08-00:00:02

Longmore: Yeah, I'm fine, I'm fine.

08-00:00:03

Lage: Okay. You've mentioned off tape that you thought of some teaching-related things.

08-00:00:09

Longmore: Yeah, well, specifically in terms of my disability in teaching. Where to start—I think the best thing about my teaching is the lecturing.

08-00:00:33

Lage: Yes. In terms of your abilities.

08-00:00:35

Longmore: Yeah. I think that's what I'm best at. Not so good at discussion—discussion-leading, which is the hardest kind of teaching. I don't feel bad at it, it's just that I'm best at lecturing. It's also a lot easier. I don't use visual aids, I don't use PowerPoint, I can't write on the board. I used to have a grad student assistant write words on the board; now I just spell out words. Students have complained that I talk really fast, and it's hard to take notes, and I jam pack my lectures with all kinds of information and ideas. I've had quite a number of students say to me, "I've got three times as many notes in this class as in any other." Or, "I've got as many notes for this one class as all the other classes combined." I tell them that my lecturing is a form of disability recruitment. They're all going to get repetitive stress injury. So I just rely on my ability to communicate.

08-00:01:48

Lage: Do you acknowledge, or talk about your disability in the first class?

08-00:01:52

Longmore: Well, that's part of what I was going to get to. I *do* talk about disability in the first class, because I say, "If you have a disability and you need accommodations, talk to me about it. We'll work it out whatever it is you need." And a lot of students with hidden disabilities, who are the majority of students with disabilities, will not talk to me about it unless they have to, unless they absolutely have to. So I had a guy a couple of years ago who blew the first midterm because he didn't know he had disability [accommodations] and what accommodations he needed. And I said to him, "You know, I made the announcement at the beginning, we could have worked this out, and you could have done a lot better. There's no shame in this. You're entitled to it. I'm one of the people who fought to get you this right! So I of all people am going to provide you with the accommodation."

So I talk about disability in that way, and it's obvious that I have a disability because from the very first day I will say to a student, somebody sitting on the front row—"Will you please take these syllabi and hand them out?" or if there's a handout—"Will you take these handouts and distribute them?" So I

don't try to mask my disability in that way, and there'll be times before class when I'm chatting with students that in conversation I may mention something about my disability rights advocacy work. It'll come up in various ways. Or they'll say—"You know, I saw the article in the newspaper—interviewing you about that." Or, "I saw you on the news when you were interviewed." So I'll talk about it then. "I saw that you're going to give a lecture on this disability rights-related topic. What's that all about? What are you doing?" With the grad seminar I teach, before and then during the class break, there's a lot more time for talking so they get to know me better and I talk about it maybe then, but I don't do it in class. I mean, the subject in the course is early American history, it's not me and my disability.

08-00:04:27

Lage:

Right. Do you incorporate disability into early American history?

08-00:04:31

Longmore:

No, I don't. I haven't, not that I couldn't, but I've got certain things I have decided I have to cover that fit with the basic way I frame American colonial history. Before you start teaching you think, "How am I going to fill up the time?" After you start teaching just for a little while, you realize there's not enough time. I can't fit everything in. So I made certain choices about what I'm going to cover. There are a lot of things I could cover that I don't get into.

There was a discussion—actually there have been a couple of discussions on some of the disability studies listservs by younger faculty members, recent PhDs, who have disabilities of various kinds, and they raise a question about disclosure. Some of them have hidden disabilities, some of them have visible disabilities, and they seem to feel uncomfortable, some of them, many of them kind of agonize over their obligation to explain their disabilities to their students. I didn't get into any of those discussions. Maybe I should have, I don't know. My reaction was, I'm under no obligation to explain anything to anybody about my disability. Those students are not there because I'm disabled. They're there because I'm a specialist in early American history. When I start to teach, I expect that they will realize that there's a lot about early American history that they can learn in this class.

Well, some of the concerns of some of these younger scholars was, well, how do I put them at ease, how do I make them feel comfortable with my disability? That is *never* a concern of mine, not in class. I only teach electives, so nobody has to take any class from me. Well, they may find themselves kind of pressured into doing so because there's a shortage of courses, but then that's their hard luck that they end up having to take a class with me.

08-00:07:06

Lage:

Would you feel any different if it wasn't an elective?

08-00:07:08

Longmore:

No, I wouldn't. Well, I taught the U.S. history survey, and that's a required class, although there are other kinds of courses you could take to fulfill the same requirements. In any case, whether it's elective or required or they felt pressured into taking because there wasn't anything else, it's not my concern. If they feel uncomfortable with me because of my disability, they don't have to be in my class. I'm not going to try to, I don't feel obligated to put them at their ease. I think what should make them feel comfortable is they're being taught by somebody who knows the field, and there's a lot they can learn. So, I don't, I don't worry about that.

How long ago was it—I guess it's almost four years ago now, I started to use a wheelchair and that meant I needed to use the ventilator. Prior to that time, I had stood up behind a lectern, and I guess it was the first semester, I elevated the wheelchair seat and sort of half stood, half sat to lecture and I wasn't using the ventilator. And then it became a lot more difficult. I couldn't stand anymore and I was having a harder time breathing, so I had to sit down to do the whole lecture. I switched from paper notes and outline to a laptop computer, with the same outline on the computer and a foot control so that I could scroll up and down within those documents, and I felt very uncomfortable using the mouthpiece, the ventilator, because I thought it was a lot harder to understand me. And maybe as important as that, or more important than that to me was, it slowed down my delivery, it screwed up my timing.

I would say to the class at the beginning of the semester and at other times, "If you can't understand what I'm saying because of this mouthpiece, stop me and ask me to repeat it. There's no point in me blathering on if you're not getting what I'm saying." But hardly anybody ever does that, and I always feel like maybe they're just not asking me to repeat because they didn't get something. And I can tell sometimes when I look at people's essays that they *did* misunderstand what I said! So that took some adjusting because I really like lecturing, and the first semester I thought, I'm not enjoying lecturing now, I don't want to do this. But by the end of the second semester of using the ventilator, I felt a lot more at ease. I felt like I had sort of regained my sense of my comfort and facility in lecturing and just decided this is the way it is and it's plenty good, and in all egotism, I said to myself, "Hey, you're still better than most of the people whose classes you sit in on, you know."

08-00:10:39

Lage:

[chuckling] Is it the sitting down that requires the ventilator?

08-00:10:42

Longmore:

Yeah, yeah. It's a lot harder for me to breathe sitting down. I still miss lecturing without the vent because I could—well, I could pack a lot more in, that's one thing.

08-00:10:54

Lage: You like to pack it in, I can tell!

08-00:10:55

Longmore: I do, I do! So, I don't know, my breathing has actually improved again because I've lost some weight, and I'm wondering if by next fall when I go back to teaching, there will be enough improvement that I can start half standing, half sitting with the elevated chair again and not use the vent. I mean, we'll see. I'm going to experiment with it, but it's okay. But I never explain this to any students, "I'm sorry I've got to use the ventilator. I really apologize; it's so hard." I'm not apologetic, but I just want to make sure they're getting what I have to say.

08-00:11:34

Lage: Yeah, yeah, very focused on your teaching.

08-00:11:37

Longmore: Well, it's the content of the course that matters, you know.

08-00:11:39

Lage: Yes.

08-00:11:40

Longmore: In a disability studies or disability history course, I will talk about myself, although I'm a little bit hesitant to do that, not because I'm embarrassed to talk about my own life experience, but because I don't want the subject of those courses to be me! The subject is disability history, or the study of disability in general.

08-00:12:04

Lage: Let's talk about that on this campus. Is there a disability studies community here?

08-00:12:11

Longmore: Not a community, no. There's the Institute on Disability, who are five faculty who ten years ago came together and approached the president and said, "We want to set up this institute. We can get outside money."

08-00:12:26

Lage: Yes. They like that.

08-00:12:28

Longmore: And he liked that, yeah. And—

08-00:12:30

Lage: And who were your five people?

08-00:12:31

Longmore: They were from different departments—one from engineering, one from rehabilitation counseling, one from special education, one from philosophy, and me. I'm the only one left.

08-00:12:44
Lage: Oh, really?

08-00:12:44
Longmore: Yeah.

08-00:12:46
Lage: Did they retire?

08-00:12:47
Longmore: Two have retired completely. One is approaching retirement, and a fourth is doing other kinds of projects, so I'm basically it now.

08-00:12:59
Lage: It was an interesting mix, though, that got it going initially.

08-00:13:02
Longmore: Yeah it was, and I wasn't the instigator of it, I—

08-00:13:04
Lage: Who was?

08-00:13:05
Longmore: These other folks, particularly the professor in rehab counseling, Alice Nemon [spells]. She was a real go-getter. So we—

08-00:13:19
Lage: And the initial money, was that—

08-00:13:20
Longmore: Well, we got various grants, mostly they ended up being training grants affiliating, collaborating with independent living centers in the Bay Area, things like that. I had hoped to see academic humanities and social sciences disabilities studies courses. That's not come off. We've sponsored a number of workshops and symposia and conferences. We got the first NEH Summer Institute that was on disability studies.

08-00:13:53
Lage: I want you to talk about that. It sounds like that must have been an important event.

08-00:13:57
Longmore: It was.

08-00:13:58
Lage: Is that—

08-00:13:59
Longmore: It was the first time NEH funded anything in disability studies. It was the first time they did one of their summer institutes, which are hard to get, on disability studies. It was the first time anybody in the faculty at San Francisco State had gotten an NEH Summer Institute. I felt very proud when I got it, and

I told two of my colleagues in history, kind of bragging, and they said, “Oh, yeah, I thought of applying for one of those but it seemed like an awful lot of work.” And I thought, “Oh, what have I done! What have I gotten myself into.” And it was. I never worked so hard.

08-00:14:31

Lage: I’ll bet.

08-00:14:31

Longmore: But it was a big turning point in disability studies. We had twenty-five faculty from around the country.

08-00:14:39

Lage: Of university—

08-00:14:40

Longmore: Colleges and universities of various sizes.

08-00:14:43

Lage: Yes. In the humanities.

08-00:14:46

Longmore: In the humanities. English, history, well—anthropology, religious studies, things like that.

08-00:14:55

Lage: Now who, how did that idea originate?

08-00:14:57

Longmore: Well, it wasn’t my idea. Rosemarie Garland-Thomson had wanted to do this, and she, at that point, was located at a university that was not receptive to her doing it there, and so she said to me, “How’d you like to work with me on this? We could do it at San Francisco State.” And I said, “Okay, yeah, let’s do it.”

08-00:15:17

Lage: Did your connection with her come through SDS [Society for Disability Studies] or—?

08-00:15:20

Longmore: Yes, yes, it did. And the people who’ve come out of that summer institute have really done a lot of work. They organized conferences on their own, they organized sessions at academic gatherings, they published, not just articles and books, but special issues of journals in their disciplines. So it—

08-00:15:47

Lage: It was a catalyst—

08-00:15:48

Longmore: Yes, it was. It was a catalyst for a lot of other stuff.

08-00:15:50

Lage: Do you want to mention any in particular? Or talk about the conversations that went on? Would that be of value?

08-00:15:57

Longmore: I'll give you just one story that I think illustrates the significance of it. An NEH program officer comes out in the middle of the summer institute to observe you for two days. So this guy comes out, and he admitted to us later that they had been a little bit uneasy: was this going to be political correctness; did it really have intellectual significance, this disability studies thing? The two days he was there we had Nancy Eiesland [spells] she's a professor of religious studies at Emory University in Atlanta. And she was our teaching and faculty person for those two days. So this guy, who was trained, I believe, in cultural anthropology, this program officer sat in on the discussions. Nancy would lecture, and we'd have a discussion based on the readings she had assigned. And I was moderating the discussions that day and at one point the program officer turns to me, and he says, he raised his hand, "Is it okay if I make a contribution to the discussion?" I said, "Sure." So he tells Rosemarie and me later, "We weren't sure about this, but disability is important stuff. It really does connect with a lot of other things." So I thought that was a real important positive result.

There were people there who in our closing session, well, our closing reception, said this had been one of the most important experiences of their lives. The third week, maybe the second week—

08-00:17:57

Lage: How long did it go on?

08-00:17:58

Longmore: Five weeks. At lunch one day, a group of the participants, who were saying how much they were getting out of this, and I mean, I was doing a lot of work. The logistics—I thought, a guy who's not a good administrator trying to run a thing like this? This is nuts! Anyway, so I had two grad students working for me who I had running constantly. They were really annoyed with me, because I had said to them, you'll get a chance to sit in on the sessions and learn a lot. And they didn't get a chance to sit down for one minute. I had them running all over the campus, because you have twenty-five people living in a dormitory for five weeks. They're not in their own bed, they're eating dorm food, and they get cranky!

We had decided early on, we were told the thing that sabotages these institutes is logistical problems—you know, people have complaints about the food, or the housing, or some—the bathroom, something, communication facilities. We decided what we had to do was—these two students, and I, and Rosemarie would go around to everybody every day and say, "How are you doing, what do you need, got any problems? What can we do?" And I would immediately send one of these two grad students to fix it. And we kept everybody happy

for five weeks. So what they were saying at lunch, this is like the end of the second week, and they're saying how much they're enjoying this, how much they're getting out of it, and one guy turns to me and he says, "Are *you* enjoying this?" And I said, "I think it is something I will have enjoyed." That went really well. [laughter]

08-00:19:42

Lage: [chuckling] And did most of the people who come have disabilities that required accommodation?

08-00:19:49

Longmore: No, no, about a third, about a third had disabilities.

08-00:19:52

Lage: Had they been people who had been working in the field of disability studies?

08-00:19:56

Longmore: Some had to some degree, but for most people it was new stuff.

08-00:20:00

Lage: Yes. Oh, really! I wonder—how does it work? You set up this institute and people apply.

08-00:20:07

Longmore: NEH issues the announcement—there's going to be, here are the institutes we're going to offer next summer. And you write to this person at this university that's hosting it and you apply, and they'll send you the information, and then they'll tell you what you need to do to apply to be accepted. So we—

08-00:20:28

Lage: And do they get funded to go?

08-00:20:30

Longmore: Yes.

08-00:20:30

Lage: That's part of the—

08-00:20:31

Longmore: Part of the budget is paying for their time there. I mean, it's not profitable, it's just—you know, it doesn't cost you. We had twenty-five slots. We had just under sixty applicants, so Rosemarie and I went through the applications and picked out the people that we thought would provide the most variety and balance.

08-00:20:59

Lage: Yes. Did you think about whether they had disabilities? Or could you tell, even.

08-00:21:03

Longmore: Everyone mentioned it. We wanted to have a balance of disabled and non-disabled people, but we didn't decide on the basis of disability. I mean, there were a lot of factors involved. Discipline—okay—we got more than enough English people, more than enough historians. Those were the two biggest groups. We wanted some other people, and there's people that we could have accepted, but we thought, well, if we include that person, then we're going to have too much of one kind in terms of scholarly interests, and we want variety here. They each wrote essays. We wanted to get a mix in terms of geography, the size of the institution they came from. Sue Schweik from UC Berkeley was one. We also had a woman from a small college in northwestern Pennsylvania, you know. So, we strove for as much variety as we could get.

08-00:22:11

Lage: Hmm. How was it set up? You mentioned a certain person would lead.

08-00:22:17

Longmore: We had a set of teaching faculty who would come in for two days each and they would talk about their areas of research interest.

08-00:22:30

Lage: So they weren't part of the group.

08-00:22:31

Longmore: They weren't part of the group. And they were only there for a couple of days each. And again, we had a variety of disciplines. History—

08-00:22:42

Lage: Did you take any of that?

08-00:22:43

Longmore: I'm sorry?

08-00:22:44

Lage: Did you take any role there as a teacher?

08-00:22:47

Longmore: Well, yeah, yeah, actually what happened was, they would do a presentation, they would assign readings, and then there would be a lot of—we wanted a lot of discussion. There would be a lot of plenary discussions. And Rosemarie and I would participate very actively in that, and I—[chuckling] this also is very egotistical. I thought, “Hey, this is my institute. I'm going to speak up as much as I want as with my classes. There's a reason it's here at my university. There's a reason I'm the co-director and Rosemarie and I are directing this together. We've been doing this a lot longer than anybody. And there's a lot of people have to learn from us.”

So I wasn't very—well, and the other thing was, the twenty-five participants and Rosemarie and I were the continuity. The teaching faculty came in for two days and left. So they weren't a part of what preceded or what followed and

we were to provide the coherency of the whole institute. So for that reason also I felt free to speak up and to say at times, “What so and so is saying now relates to what so and so said last week,” and then to put my own larger interpretation on it if I felt warranted in doing that.

08-00:24:21

Lage: Did, in your own mind, anything happen during this institution that led you off in—

08-00:24:28

Longmore: In terms of changing my thinking?

08-00:24:28

Lage: —different directions, or.

08-00:24:29

Longmore: In terms of changing my thinking.

08-00:24:31

Lage: Yeah, yeah.

08-00:24:31

Longmore: [pause] It’s been five years.

08-00:24:41

Lage: Right, well, this was 2000, I don’t know if you ever mentioned the date.

08-00:24:42

Longmore: It’s six years, yeah, six years. It was in the summer of 2000, June and July. I’m trying to think of how I—well, I, most of what *I* learned had to do with administrative logistics! [chuckling] That was really a benefit for me, personally. I did get exposed to readings I was unfamiliar with. It was much more at a personal level rather than an intellectual level, I think, for me. It certainly reinforced my sense of the real value of historical study—

08-00:25:30

Lage: As opposed to other types of study?

08-00:25:33

Longmore: As opposed to disciplines that don’t have as much regard for evidence. There was a moment when the historians in the group got pretty frustrated with some people in other disciplines who—

08-00:25:53

Lage: Such as—

08-00:25:54

Longmore: Some lit people who they sort of felt were rather cavalier about things like historical evidence, periodization. I’ll give you one example. One of the teaching faculty [David Mitchell] talked about something in French cultural history. We had a French historian [Catherine Kudlick] there, and she said,

“Well, you’re off by about a century, that’s from the sixteenth century, and you’re talking about the seventeenth century.” And I said to her, “Well it really isn’t this—what they’re saying is more relevant to the eighteenth century French Enlightenment.” And she said, “Yeah.” And basically, the person [Mitchell], the teaching panel member who said this, shrugged, like it’s not a big deal—so what’s a century here and there.

08-00:26:45

Lage: [chuckling] That’s interesting.

08-00:26:47

Longmore: Yeah. So, that was a moment when I—that kind of concern, that kind of critical reaction on my part exemplified a larger problem I had been having and continue to have with humanistic disability studies—a lack of rigor, a lack of empirical research—what’s called theorizing—

08-00:27:29

Lage: Well, that’s what I was going to ask you—theorizing.

08-00:27:30

Longmore: Well, it’s called theorizing, but it’s not real theorizing. It’s speculation off the top of one’s head, without a real basis in hard evidence-based research and analysis.

08-00:27:45

Lage: But making use of critical theories, or—

08-00:27:49

Longmore: Well, it makes use of jargon and invented concepts, but it doesn’t test those concepts, and I think it’s a real serious weakness in a lot of humanistic disability studies these days, which is the dominant disability studies currently and has been for about a decade, and I think it’s a really serious problem.

08-00:28:10

Lage: Could you give some examples.

08-00:28:12

Longmore: You want me to name names? [chuckling]

08-00:28:16

Lage: In a way, yes. [chuckling]

08-00:28:20

Longmore: I’m not sure—you know, if I name names people are going to say, “Yeah, see, I knew he was out to get me.”

08-00:28:29

Lage: I know. I know this is a problem. I need it for my own self, maybe you can tell me later, but—[laughter] But, I just think this is a really important thing for scholarship—

08-00:28:39

Longmore: I think so too.

08-00:28:40

Lage: And for disability studies.

08-00:28:41

Longmore: Well, let me bring up another point about something that I'm critical about in current disability studies. Many of the scholars in disability studies who are again, overwhelmingly, in the humanities, do not have a sense of the history of disability studies. Disability studies in the U.S., in the 1980s, started out with people in the social sciences and policy fields, whether as policy advocates, or policy makers, or students of policy in academia, and they *were* trained in rigorous social science methods. In the early nineties, on into the mid-nineties those people began to exit disability studies and humanities people began to take over.

08-00:29:32

Lage: Now, why did they exit?

08-00:29:33

Longmore: I think they felt crowded out. I had wanted humanities people in disability studies, because in the eighties, I was just about it. I was the only historian. I don't know that there were any lit people in the eighties. Rosemarie Garland-Thomson started to get into it late in the eighties, because she was at Brandeis, where Irv Zola was, but Irv was in sociology, remember.

08-00:30:05

Lage: And she is in—lit.?

08-00:30:07

Longmore: She's at Emory now.

08-00:30:08

Lage: No, but her field.

08-00:30:08

Longmore: Lit.

08-00:30:10

Lage: Lit.

08-00:30:10

Longmore: American literature and women's studies. She's actually in the Women's Studies Department. So I felt that there was a big loss with the exit of social sciences people from disability studies. It's really unbalanced now. The other thing that—

08-00:30:31

Lage: And history kind of straddles those two.

08-00:30:35

Longmore: Yes

08-00:30:36

Lage: Go ahead, I interrupted your—

08-00:30:37

Longmore: The other thing that's related to that is the people in early disability studies in the U.S., as with disability studies in Britain were very politically minded. I mean, we thought of disability studies as serving the disability rights movement by providing rigorous critical analysis—research and analysis. Any movement for social change needs that. Certainly dominant interests in any society have their own scholars and researchers and analysts who present the case and substantiate with data. We did that too, we felt.

08-00:31:26

Lage: But there must be a tension there between serving a movement and seeking the truth.

08-00:31:31

Longmore: Well, there is, yes, yes, there is a tension. It doesn't serve the movement if you're just producing propaganda. So I always wanted disability studies scholarship to be rigorous and sound. The difficulty with a lot of people who've come into disability studies in the last decade in the humanities is they haven't been a part of the political movement at all. The people in the eighties, the social science people, knew a *lot* about public policy and disability. A lot of the more recent—they tend to be younger scholars also, they're not only not political, they have very little knowledge of policy. It keeps having to be explained to them. And I think a lot of them don't—they have trouble grasping it—so they're disconnected from the political movement, the political community, and they're not knowledgeable about policy, and I think that really weakens disability studies analysis that they do. They've contributed other things.

08-00:32:44

Lage: They seem more, I don't know if theoretical is the right word, but—

08-00:32:49

Longmore: Well, that's the word they use.

08-00:32:50

Lage: Embodiment and—

08-00:32:52

Longmore: Yes, they use a lot of imported concepts borrowed from postmodernism.

08-00:33:01

Lage: And literary theory.

08-00:33:04

Longmore: And literary theory. And I mean, I have trouble with scholarship in any field that employs concepts that it doesn't critically analyze or test. One of my beefs with historians is that somebody will come up with a thesis which is essentially a historical theory about what happened. And other historians, instead of testing it, sometimes will just apply it. They take the—

08-00:33:39

Lage: Use it to explain.

08-00:33:40

Longmore: —evidence they've got—they take it—yeah, oh, this explains that, this evidence I've got, instead of saying, "Well, how does the evidence compel me to moderate or modify that thesis." And I'm not saying that across the board, but that's happened at times. I think the same thing is true in disability studies.

08-00:33:56

Lage: But sometimes historians are criticized for *not* making use of theory.

08-00:34:01

Longmore: That's right. Historians are not theoretical enough. That's true.

08-00:34:04

Lage: Do you feel that about your own work? Or—

08-00:34:07

Longmore: Oh, not my work! [chuckling]

08-00:34:09

Lage: I mean, where do you stand in that continuum?

08-00:34:12

Longmore: Well, I've been trying to make my, certainly, disability-related, disability historical and disability studies work, more theoretically grounded. The recent work I've done in early American history is much more theoretically grounded. The stuff I'm working on now is about nationalism and the coming of the American Revolution, and I'm drawn to the theoretical social science literature on nationalism, of which there is a great deal that early Americanists have not tapped. There aren't very many historians doing nationalist studies, and certainly not in early American history.

I've also had a couple of journal articles published in the last couple of years—well, one's been published, one is coming out—on early American English, the evolution of the English language in the colonies, and relating that to the emergence of American nationhood, and so I've done a lot of reading in historical linguistics and sociolinguistics and some of it's real technical. I'm not sure how well I understand it, but I understand enough that I think that I can apply it to early American history and make a case for the relationship between the evolution of the English language in seventeenth and

eighteenth century America and the emergence of American nationalism or nationhood. So there I'm trying to be more theoretical, and I'm hoping that I'll do a series of articles and hopefully a book on revolutionary nationalism, the origins of it, that will be more theoretically grounded. In terms of disability studies, I'm trying to do that—that's multidisciplinary, I mean, any kind of good disability studies needs to be. So—

08-00:36:17

Lage:

Does someone like Rosemarie Garland-Thomson use her evidence well? I mean, she definitely uses a lot of literary theory.

08-00:36:28

Longmore:

But a lot of what she's doing is explicating literary texts. It's not for me to tell people who are literary critics how to exegete a text. I don't know how to do that, and I respect their work in that area. I have a bit more difficulty with more general assertions about disability. There's some work—well, there's a collection of essays that the MLA published called [*Disability Studies:*] *Enabling the Humanities*. It's disability studies in the humanities, and some of the stuff in there is really good. The stuff I think is good is stuff that's grounded in a careful reading of evidence. To take one example—I'm kind of blanking on her name—[tape interruption]

08-00:38:02

Lage:

Okay. We're back on and you were talking about a particular article, I guess.

08-00:38:07

Longmore:

Well, one of the essays I really admire in that collection is by Martha Stoddard [spells] Holmes [spells]. She was, in fact, one of the participants in the summer institute, and it's about disability in Victorian literature, certainly, as I recall, in that essay it's disability in Dickens. And it's really good solid literary historical work. There's some other stuff in there that's very abstract. It seems to me it just kind of plugs concepts into disability from other fields, from other areas, from other quote-unquote theorizing, and it doesn't modify it to fit disability because the people writing that stuff don't really know that much about disability. They don't understand disability.

08-00:39:04

Lage:

It's too far from the lived experience, are you saying?

08-00:39:09

Longmore:

It's too far from real research *or* the lived experience. There are some other essays that are more personal that are grounded in lived experience. There are others like Martha's that are based on research, but there still is something in disability studies that to me is abstract and distanced from either the personal or the historical reality of lived disability, and that's what I want to see more of.

08-00:39:41

Lage:

And is it—go ahead.

08-00:39:43

Longmore: Well, I want to see more grounded research.

08-00:39:47

Lage: Grounded research and what about relationship to advocacy? Is that missing?

08-00:39:52

Longmore: Yes it is. There's an attempt to advocate or to support advocacy, but since some of the people writing this, really don't know a lot about policy or past activism, or most important, understanding the issues we've been grappling with, I think they're kind of off base in their perspective on things.

08-00:40:20

Lage: Is any of this related to whether these scholars have a disability?

08-00:40:30

Longmore: It may be the case that with some scholars not having a disability makes it harder, but I know lots of nondisabled people who do have a very clear understanding. I also know people with disabilities who don't get it.

08-00:40:47

Lage: I think I've read or been told that some people kind of resent people without disabilities getting involved in disability scholarship.

08-00:40:59

Longmore: Well, the question that's been raised in the past, like in the early nineties, one of the reasons I think some of those social science people left the Society for Disability Studies, was, a question was raised that became quite controversial. What's the role of nondisabled people in disability studies? That's been an issue in the disability rights movement as well. And I think some people felt rejected, wounded, and unwanted, and they exited. But there were some legitimate questions being raised, that is, for instance, there are a lot of nondisabled scholars, like there are nondisabled people in all kinds of occupations who have advantages, privileges, who have access to resources that many disabled people don't have, that they can't get to. They've been discriminated against. So there needs to be an acknowledgement of those privileged positions.

Also, there needs to be an acknowledgement that one has to approach this, I think, with a certain humility if you're coming from outside an experience. That's certainly true with men working on women's issues, or white people working on scholarship or issues related to people with color, and if anything, it's even more true regarding people with disabilities. All of us have been socialized into acceptance of the idea that it's entirely appropriate and probably preferable for nondisabled people to be the ones in charge, as they usually are, to have the power, and people with disabilities to submit to their authority and their superior expertise. I think we all fall into that to one degree or another. It's automatic, it's reflexive, it's unconscious. It doesn't indicate necessarily bad motives, it's just the way we've all been taught.

08-00:43:15

Lage: You mean all of us—disabled and nondisabled as a group.

08-00:43:17

Longmore: Disabled and nondisabled alike, yeah.

08-00:43:19

Lage: Right.

08-00:43:20

Longmore: A lot of people with disabilities unconsciously fall into letting somebody without a disability take the lead, and they hang back. So that's a dispute that's come up time and again. It's also the case that some people with disabilities have a harder time asserting themselves, maybe because their disability involves limitations in the ability to communicate. I think it's the responsibility of people with disabilities to assert themselves and reflexively of nondisabled people to *check* themselves. I do lecturing to, for instance, physical therapy classes, grad students in PT at San Francisco State. And one of the things I say to them is, in your practice, when you're in rehabilitation and you've got a patient with a disability, you should listen to them. Not that they know everything; there are a lot of things they don't know and can learn from you, but a lot of us are really pretty expert about our bodies and the kind of conditions we have and what works for us or doesn't work for us. And you could learn a lot. The same thing applies to scholarship.

08-00:44:42

Lage: I'm just thinking about the case of the historian, where the very nature of the business, or the enterprise, is to put yourself in other's shoes, either in another time period, a different nationality, a different race. How does that apply to—

08-00:45:02

Longmore: Well, that's why I say, look I teach early American history—what's it about—race, gender, class—

08-00:45:08

Lage: And a time period that you haven't lived through. [chuckling]

08-00:45:11

Longmore: Yeah. Military conquest, colonization. Who did I write about? A rich, elite white man—George Washington. I don't know his experience either any more than I know the experience of any of his slaves from the inside. I teach about all this stuff. I think the study of history ought to teach one a certain amount of humility. I think the same thing applies to the study of disability.

I got into a huge clash with a leading disability studies scholar last year over the issue of physician-assisted suicide. And I felt this person really did not understand the history of opposition by disability rights activists on that issue. This is a non-disabled person who has an entire right to favor legalization, but was scolding and even accusing disability rights activists and disability studies scholars like me of intimidating other people, of browbeating them, into

acquiescing to our position. One of the things I pointed out at the time was back in the eighties and on through much of the nineties, I and other people were pretty much lone voices in the disability rights movement in opposing assisted suicide. Most people didn't want to touch it, or they were on the other side, and very gradually we changed minds. And this person I was feuding with just didn't know any of that and was just accusing us of being censorious.

08-00:47:09

Lage: Hmm. I think, unless we have something to wrap up, we should maybe stop here—

08-00:47:16

Longmore: Okay.

08-00:47:16

Lage: —and have one final session. But is there any more to wrap up on this issue?

08-00:47:19

Longmore: I don't know!

08-00:47:20

Lage: We can come back to these thoughts next time.

08-00:47:25

Longmore: Yeah, yeah, sure.

08-00:47:26

Lage: The course of disability studies and this issue of the perspective of the person with a disability. But we've gone a long time, and don't want to get into a new issue.

08-00:47:35

Longmore: No, no, I understand.

08-00:47:37

Lage: [tape interruption] Okay—we thought of an addendum here.

08-00:47:41

Longmore: As long as we're talking about the state of disability studies, one of my hopes for a long time, connected with the idea of encouraging rigorous research, is the, I guess for want of a better word, I'll call it the professionalization of disability studies, that is, that we would develop a field along professional lines. It's very hard to make a multidisciplinary effort succeed, because the disciplines are so varied in their approaches and methods, but nonetheless we could be professional about everything. A lot of what goes on with disability studies, at least in terms of the discussion, it seems to me to be kind of more about personal grappling with identity, than, say, an analysis of the formation of social identity from a scholarly approach, if I'm being clear about that.

08-00:48:53

Lage: You mean talking about personal experiences—

08-00:48:56

Longmore: Yeah—too much.

08-00:48:57

Lage: —in classes? Or in writing?

08-00:48:59

Longmore: Well, at least in the listservs, I mean, I pretty much exited the listservs. The, one thing that really troubles me along this line of professionalization is both of the two major disability studies listservs in the U.S., the SDS listserv and the Disability Studies in the Humanities listserv, have now decided to close their archives. Now, every other listserv, every other academic listserv I'm on has open access to their archives. You don't have to be a subscriber to get access to those archives, so you can see past discussions. There's a great deal of timidity, it seems to me, among disability studies scholars that something that they say or that is said on one of these listservs will come back to haunt them. I'm not sure who it is they're afraid of. I was accused of being one of the people who was intimidating them, that I would come back to haunt them. I'm very troubled at the closing of the listservs, making them so private.

08-00:50:17

Lage: Do you know who made that decision?

08-00:50:19

Longmore: It was a collective decision, it looks like, on the part of the managers, and a lot of the participants, and the SDS listserv now has this warning about—it's got these guidelines about how private all this is, you can't repost stuff. That's not something I see on other listservs either—ways to register complaints. Well, I think moderated listservs that, you know, prevent flaming is a good idea. But taken altogether, there's a fear about speaking up clearly and directly and frankly. One of the things I said in this dispute that occurred last year was, if any of us, especially younger scholars, are afraid to speak out and express our views, maybe we're in the wrong line of work, because my experience of intellectual discourse in graduate study and in the academy has been that it is very vigorous, and at times it's really fierce, and you've got to have a thick skin, and you better be prepared to state your views and stand your ground and be ready to change in the face of stronger arguments or better evidence. But what you can't do is shrink back. And I also tried to say that it doesn't serve the interests of people with disabilities, the disability communities, the disability rights movements for those of us in disability studies who are supposedly there to provide an intellectual foundation. It doesn't serve the interests of that movement at all if we're afraid to grapple with really hard questions, really tough, scary issues.

08-00:52:16

Lage: And did you get responses to that?

08-00:52:18

Longmore: No, I didn't.

08-00:52:19

Lage: [chuckling] It's hard to answer that.

08-00:52:21

Longmore: Well, what I got was silence on the one hand and then some criticism on the other, not from that particular statement but from the general disputes. And so I just decided that I wasn't going to waste my time any more on those listservs, that the discussions were becoming so, in general, fatuous.

08-00:52:50

Lage: Well, did you get criticism for your point of view or your insistency or tone, or whatever.

08-00:52:59

Longmore: It depends on who you're talking about. Some people are just scared that I was so emphatic, because I took on, the person that—well, Lennard Davis at the University of Chicago was the person I was talking about earlier who accused me, in particular, and other people of intimidating the other scholars.

08-00:53:20

Lage: On the issue of right to die.

08-00:53:23

Longmore: On the issue of his position on the right to die. And he went public on NPR in a commentary and in *Inside Higher Education*, an online periodical and he—

08-00:53:33

Lage: —and mentioning you.

08-00:53:34

Longmore: —not me specifically, but he said that in *Inside Higher Education* that some people in disability studies, senior scholars, were intimidating and censoring younger scholars, and this was a really serious charge. It's questioning the integrity and the professional ethics of a number of people, and I thought it was harmful to the field, and I wanted the leadership of disability studies to address it. Most people didn't want to address it. They just ignored it.

08-00:54:08

Lage: Hmm. And he comes right out of the University of Illinois, Chicago.

08-00:54:15

Longmore: Yeah, but he's not in the disability studies program, he's an adjunct to it. He's the head of the English Department there, and I felt that this was undermining the field to have these kinds of accusations. I asked for the SDS board to investigate. If this is true that this kind of intimidation is going on, something needs to be done about it. Well, he didn't provide evidence, he said he couldn't, that the people who had confided in him were afraid to have their names revealed, and this was all very convenient, I thought. The SDS board

didn't want to pursue it, so I felt there was a failure of leadership there, and I think that SDS is much weaker because of it, and it's weakening. So I'm focusing my own energies at this point for the foreseeable future on my own work and on the Disability History Association, which I hope will build professional scholarship in disability history.

08-00:55:27

Lage: More focusing on your discipline, really.

08-00:55:31

Longmore: Yeah, I am. I think that there's also still, in all this work, whether it's history or disability studies in general, there's relevancy to what's going on in the world, and anybody who wants to get into this better be prepared to struggle with hard, painful, controversial issues and to have intellectual honesty and some gutsiness about speaking out. I find disability very hard to work on, whether it's advocacy or scholarship. I find a lot of it very painful.

08-00:56:21

Lage: Just because of personal—

08-00:56:23

Longmore: Not just personal stuff, some of it relates to me directly personally, but mostly it has to do with having to come to grips with the depths of the devaluation and the contempt of people with disabilities that occurs and has so often occurred. That's not easy to have to look at and to think about. I find it scary. I find it—as hideous as a lot of early American history can be, I mean in terms of oppression, it's very distant, so I find it easier to deal with that kind of stuff, in a way, than with a lot of what I do with disability studies and disability advocacy. I think we need our movement and community in order to bolster one another up to deal with hate all the time. I wouldn't and couldn't do it by myself.

08-00:57:27

Lage: Hmm.

08-00:57:27

Longmore: Let's stop there.

08-00:57:29

Lage: I think so. Good.

[Interview 5: November 8, 2006]

[Audiofile 9]

09-00:00:00

Lage: Concise, I must say, I think you've been very concise. Okay. Today is November 8, 2006, and this is our fifth session, Paul. Paul Longmore, and I'm Ann Lage, and we think it's going to be our final session; that's what we're aiming for, so let's plunge ahead. Last time we talked some about disability history, and I was wondering what the reaction of historians has been to your effort to sort of bring disability history to the fore.

09-00:00:43

Longmore: Well, the first scholarly publications I produced were in the mid-1980s. A couple of review essays in a journal called *Reviews in American History*, which publishes essay length reviews that not only look at particular books but also are assessments of the field that book is a part of, and so I got the opportunity to review some books in two essays related to disability. The first one was a new biography on Randolph Bourne and the next one was three books. One, Hugh Gallagher's book, *FDR's Splendid Deception*, Harlan Lane's *When the Mind Hears: A History of the Deaf*, and the third one was Peter Tyor and Leland Bell, *Caring for the Retarded in America, A History*. I got the opportunity to do those pieces because the editor of *Reviews* had had me review two books on George Washington, which was a conventional subject, and he said he liked what I had done and if anything interested me in the future to let him know, so I immediately said, "Well, there's this new biography of Randolph Bourne, so I'd like to do that. That essay then led to the next one on those other three books. In the Bourne essay I called for historians to look at disability as a significant and useful category of historical analysis, and in the next one, the one about those other three books, I suggested some possible contours of a modern history of disability.

09-00:02:57

Lage: Now, are those two different things, Paul? Using disability as an analytical tool—

09-00:03:04

Longmore: Well, the first one, I mean, reviewed the biography of Bourne, but then it went on to say well, what's wrong with this biography, which in other respects is the best biography yet on Bourne, is that the author doesn't understand disability, and here's what we need to understand. So that was more general about disability as a concept, well, a concept as well as a historical phenomenon, so that it could be a theme of historical study and a tool of historical analysis. But the other essay on FDR and the history of deaf people and the history of mentally retarded people was along the lines of this—here are three specific histories in the modern era, in the eighteenth, nineteenth, and twentieth centuries, and if we try to take what they're telling us, we can weave them together into a more general interpretation of disability history. It has that possibility.

So that's, I mean, that's different. That's not historiographical, that's historical, that's a historical account. That's suggesting the patterns of disability history as opposed to the first essay, which was saying, "Here's a different way to look at history and an important theme in history that we need to look at." So I published those two essays. I got some responses. The editor of *Reviews in American History*, Stanley Kutler, said of the Bourne essay that he thought it was pioneering, and he was glad they were publishing it. I got some, I got at least one letter from a historian who didn't do disability history but he said, "I find this really helpful in what I am working on." And it was all favorably received but not a whole lot of reaction beyond that. There were a few sessions at historical meetings on disability history. It wasn't a regular thing though.

09-00:05:46

Lage:

Did you help bring any of those sessions together?

09-00:05:49

Longmore:

Some of them I did, some of them I just attended if I was at those conferences. In the mid-1990s, I'm forgetting the exact year, but it wasn't all that long after I got to San Francisco State, it might be, maybe '95, the Pacific Coast branch of the American Historical Association had its annual meeting at San Francisco State, and so I organized two sessions on disability history and one there were some really good papers by not only historians who were in faculty positions, but a couple of grad students as well. One of the interesting things to me, well, this is another good example of the reception—the program chair of that gathering was Martin Ridge, who was the director of research at the Huntington Library for a long time and a very highly regarded historian of the American West and of other subjects. Martin had a son with a developmental disability, and I had gotten to know him when I was doing research at the Huntington over a period of several years when I lived in southern California, so we had talked about disability-related stuff. Martin was actually kind of nervous when I told him I was going to burn my book. He thought, no, this is not a good idea. Martin's a very, was—he's not with us anymore. He was a very forceful personality with very strong opinions, and so I basically told him, "No, Martin, this is a good idea and I'm going to do it." Anyway he was program chair of that AHAPCB [meeting] and so I contacted him, and I said, "I want to organize a couple of sessions on disability history." And he was all for it.

That exemplified, I should say, the kind of people who, with regard to not just disability history and disability studies, but disability rights issues, become supporters. They are people who in some way have a personal connection. If you look at the chief authors and sponsors of the Americans with Disabilities Act in the Congress and in the first Bush administration, including President Bush himself—all of them had some personal connections.

09-00:08:51

Lage:

They don't get it unless they have it close to them, in some way.

09-00:08:55

Longmore:

They understood from their personal relationships that prejudice and discrimination were a problem, and that made them very strongly supportive of the ADA. Anyway, I organized these two sessions, and Doug Baynton, who's at the University of Iowa, where he got his PhD and is now a faculty member, who's written on deaf history and is now writing on disability and immigration history—he's a really fine scholar—he was one of the paper presenters. He said something that, well, I can date this now, it was 1995 [actually it was 1996], because he said, "Ten years ago," which would be 1985, "Paul Longmore published," well, I guess where he started was there was another historian who had published an important article on gender as a category of historical analysis and called on historians to adopt gender, not just to do women's history, but to use gender as a way of thinking about all history. He said, "The same year, Paul Longmore published a piece in which he called on historians to look at disability. Now that other article has gotten a great deal of attention, but Longmore's piece has really been neglected." And I hadn't really thought about that before, that those two pieces came out similarly—at the same time, but that illustrated what happened in that period, that is, that historians who read the pieces said, "Oh, this is good stuff, this is important; yes, we should do this." But then nobody really did.

09-00:11:06

Lage:

Now how would they do it? I—it's my own lack that I can't quite grip that. If a historian who doesn't necessarily study disability history was to adopt disability as a category of analysis, what would they—

09-00:11:23

Longmore:

Well, for instance, historians who do, say, social history, in the past might have had a kind of simplistic uncomplicated way of looking at their subjects. But now, you couldn't get away with doing a social history unless you took into account gender and race and class. Not just those, you'd not only have to use those three categories as ways of thinking about these people you're studying, but you'd also have to show how they interacted with one another, so part of what I was suggesting was we need to incorporate disability into that mix.

Before we started here, we were saying something about multiple identities. Well, disability is very complicated in and of itself because there are so many different types of disability experiences, but it becomes further complicated by the interacting elements of gender and race and class as well as other things, like religion, let's say. So that would be one key way in which it could be done. Doug Baynton's own work on disability and immigration history, that's got to look at immigrant status and ethnicity, and class, and presumably gender, and I would guess religion would be a part of it too, and disability, because all those things complicate the experience of disability and vice-versa—

09-00:13:11

Lage: The experience of disability? Or the experience of immigration?

09-00:13:14

Longmore: That too, yeah. Both. So it needs to be—it can be there in all kinds of places. I'll give you another example. There's some work on disability and labor history. Labor historians have never looked at disability, but there's a very high incidence of disability among working-class people, not only the workers, but their families. So now we've got some studies that look at disability among late nineteenth century American railroad workers and early twentieth century coal miners and their families, and that's introduced disability as a way to think about their experiences as well, so disability is really—

09-00:14:13

Lage: Military history.

09-00:14:15

Longmore: Yes, military as well. I mean, if you want to think about the rise of the modern state, you're going to look at the ways in which modern states fashion themselves through war-making, also through the development of public education, also through the fashioning of social welfare policies and programs. All three of those have disability right at the center, because a lot of war-making policy had to do with—what do you do with people who aren't killed, but become disabled and then having served the state require the state's assistance in order to live afterwards, to be rehabilitated or to be provided for in some way. A major issue in the development of public education was, what do you do with kids who don't fit into this system that we're designing—we want to either educate or regulate them in some way, you know, if they're kids with disabilities. Social welfare policy is very much about disability.

09-00:15:36

Lage: Yes.

09-00:15:38

Longmore: So it's right there, central to the history of the rise of modern states.

09-00:15:44

Lage: Now let me ask you, when we talked last week about your teaching of American history, colonial history, whatnot, you said you didn't bring disability into it.

09-00:15:54

Longmore: No—

09-00:15:54

Lage: Do you bring it in in that way at all?

09-00:15:56

Longmore:

Well, I could, I don't teach much about war, even though there's sure a lot of war. I mean, I have some lectures on early American warfare but I don't use them a lot of the time because, even though I find it fascinating, there are other things I think I really need to get into more. In terms of war, an early modern form of vocational rehabilitation appears in some of the colonial legislative enactments regarding disabled veterans. In Pennsylvania we know that disabled veterans were given licenses to operate taverns. That's really a form of vocational rehab. In Virginia, they were pensioned off. They were given a regular monetary sum, which is comparable—it's the forerunner of modern disabled veterans' pensions. No, I—well, you're nailing me in an area which I feel a little guilty in that I haven't found ways to incorporate disability more into early American history. It's certainly there.

09-00:17:30

Lage:

Yeah, but you also expressed the sense that you didn't want to appear to be pushing your agenda, or—

09-00:17:36

Longmore:

Well, no, it's not so much that—it's that I've got a particular way of framing my courses on early America that has to do with empire building, colonialism, the maturation of colonies, and the advent of nationalism that leads to separation and national independence. That's the way I've structured my courses on colonial America, and I'm real happy with that structure, so everything that I've put into the courses goes to make those points that I want to make about that.

09-00:18:23

Lage:

Interesting.

09-00:18:24

Longmore:

Yeah.

09-00:18:26

Lage:

Okay. Now where we—this—

09-00:18:27

Longmore:

Oh, disability history and the reception—

09-00:18:30

Lage:

Disability history and reception—

09-00:18:32

Longmore:

Well, in the last ten years, in the ten years since that Pacific Coast branch conference, things have changed rather dramatically. A generation of younger historians has emerged. Some of them are fairly recent PhDs. Others are still in graduate school, and they want to do disability history as a major focus of their work. They of course do other things as well.

09-00:19:09

Lage: Now what do you attribute this to? Do they have a tie to disability in some way?

09-00:19:13

Longmore: Many of them do, they have disabilities of their own, or they have a personal connection. And they now have faculty mentors who make, well, in most cases are not conversant with disability issues but are certainly open to it.

09-00:19:33

Lage: Yes. They're more open to this idea of the categories of historical analysis—gender, race, class.

09-00:19:38

Longmore: Yes, yes, and what a number of them then say to the grad student is, "Well, you should contact Paul." [chuckling] Or they call me or they email me and, "Can we talk." And so we talk about what they want to do, and I'm very encouraged by their interest and their efforts. Some of them are really fine scholars.

09-00:20:02

Lage: Are they West Coast? East Coast?

09-00:20:04

Longmore: They're all over the country, and they and the people who are in faculty positions now are presenting papers at professional meetings. There's a lot of work that's been published. I've been co-editing a series for NYU Press on the history of disability and some of these—everything we've published just about is by younger scholars.

09-00:20:34

Lage: Hmm. How did that come about—your editing of that series?

09-00:20:39

Longmore: Well, Lauri [spells] Umansky [spells] who is a history professor at Suffolk University in Boston contacted me—when was it—I guess it was '98, the fall of '98. She said, "I've got a contract with New York University Press to edit a collection of essays on disability history, and I've put out a call for proposals, and I would love to have something that you've written. And I said, "Well, I don't have anything new I could give you." And then she said, "Well, the other thing I would really like is if you would be willing to work with me on editing this." And I said, "Oh, no, I don't want to edit anybody's stuff, and I don't want to co-anything. I've co-written with people and it was always just a miserable experience, because I have my own idiosyncratic way of working—and that really would be—I mean, you wouldn't enjoy it."

09-00:21:53

Lage: [chuckling] Did you know her?

09-00:21:56

Longmore:

No. I never met her. She was one of a number of people who said to me, “I read your stuff from the mid-eighties in *Reviews in American History*, and that’s what turned me on to disability history. A number, I guess, of these younger scholars have an interest, and they found the stuff that I had written and that helped to spur them on. So she said, “Well, is it okay if I call you occasionally and just talk to you about what I’m working on.” And I said, “Yeah, that’s fine.”

So, every month or two for the next half year she would call me and we’d talk about the progress of this project and finally about six months later she—and every time she would call, she would say, “I really wish you’d co-edit this with me.” And so finally I said, “Okay. I’ll do it.” And I’m really glad I did, because she was wonderful to work with; it was a terrifically satisfying and creative collaboration. She’s a really good editor, and I think we had complementary skills to bring to it, and I also learned a great deal, not only about disability history, but about how to do history, about historical editing, and just about editing.

09-00:23:36

Lage:

Did you edit a lot of the articles that were submitted?

09-00:23:39

Longmore:

It varied, it varied. In one case I thoroughly rewrote the opening section of one of the essays, because this person really wasn’t clear about what the point of the essay was, and I read the rest of the essay—I was able to help this author—

09-00:24:01

Lage:

Tell them what they were trying to say!

09-00:24:03

Longmore:

Yeah. So it was a lot of hard work.

09-00:24:07

Lage:

Yeah, and sometimes is it just a few grammatical changes here and there?

09-00:24:12

Longmore:

Yeah. In another case, the person had written the essay entirely in the passive voice and that not only makes for dull writing, it makes things a lot longer. So I said, “You know, you’re writing about something really important here. I want readers to read it, and also it needs to be shorter. And NYU Press likes things to be very readable, because they’re interested in marketability. So, you can rewrite it yourself, or if you’re willing to let me, I’ll take a stab at making changes, and I promise you I will not lose one iota of substance from your essay.” Well, this person was pretty reluctant to let me do that. I would be too. But said, “Well, okay.” It took me a week of solid hard work. I just went through it sentence by sentence, and in almost every case, all I had to do was

recast a sentence from the passive to the active. The result was the essay was one sixth shorter than it had been, and it had a lot more energy to it.

09-00:25:43

Lage: Of course!

09-00:25:46

Longmore: So it ended up working very well. The other thing I learned from that experience about editing was—you have to be a psychologist and a diplomat as well as a historical scholar, because you're dealing with people's egos and the work that they've put a great deal of energy into—a lot of themselves are in there. I also found that the women contributors were the easier to work with, which was not surprising. And then the other experience I had with that book—

09-00:26:33

Lage: You did publish something. Didn't you publish your piece about the labor movement?

09-00:26:44

Longmore: The "League of the Physically Handicapped."

09-00:26:45

Lage: Yeah, the "League of the Physically Handicapped."

09-00:26:46

Longmore: Yeah, yeah, well, that one too, yeah. That came out in 2000 in the *Journal of American History* after a number of years of working on it, revising it repeatedly with the outside readers, yeah. The other thing I was going to say, and I don't know if this is important enough to go into was with the new disability history collection that Lauri and I co-edited, I did the index. She hired an indexer—I tease her about this—she hired an indexer, we paid her about twelve hundred bucks and it was just horrible! I think most indexes to books are worthless. So I said, I looked at it, and I said, "This is not going to do—we need a really useful index."

So I spent a month, and I did the whole index, and I developed a philosophy of book indexing in that process. You should be able to find anything that's important in a book by using the index. The index is really another chapter that involves an interpretation of the book, and so you should, a reader should, be able to not just look up proper names, but find ideas, themes, the major issues that are there, and so it needs to be on the one hand both complex but also user friendly, I guess, is the word. You have to put yourself in the position of the reader. I'm looking for something I read, and I want to look for this thing, this theme—what term would I look under? I mean—as the terms might change, a theme might appear under several different terms in the text. Now that book was really hard to index because we had fifteen essays.

09-00:29:01

Lage: Right. People using different terminology.

09-00:29:04

Longmore: Well, and each was on a different topic. So essentially I had fifteen indexes that then were integrated into a single index, but it was more complicated than that because there were themes that recurred in different essays that linked them together.

09-00:29:20

Lage: And these were things that you were interested in highlighting, in the sense—

09-00:29:25

Longmore: Oh, well, yeah, well, and I also wanted to be faithful to what the contributors were trying to say—and then I did the same thing with my own book, *Why I Burned My Book* because those were again a collection of essays written at different times on different subjects, so in a sense each had their own focus but then they also were tied together, so that was a bit less complicated than the index to the *The New Disability History*,² but I mean, it was really hard work but it was a very creative learning experience for me. I showed the index to *The New Disability History*, well, I showed the book to a friend of mine, a historian, and I was feeling pretty proud of myself, and I said, “Look at the index!” And she starts to thumb through the index and she looks at it and then she looks up at me and she says, “Wow.” And she thumbs through some more pages of the index and she says, “Wow.” And then she thumbs through again. She looks up at me and says, “You are really sick.” [laughter]

09-00:30:41

Lage: That’s wonderful! Now what about the intro? I found that to be very well written. How did you cooperate with Lauri Umansky on that?

09-00:30:54

Longmore: We wrote it together. In the initial drafts I did part of it and she did part of it and then we kept sending it back and forth. I had warned her about my idiosyncracies. One of the things that I think started to exasperate her was, I’m a slow writer and what I do when I write is I go through, well, each day I’m working on the thing I start at the beginning and I go through to the point at which I stopped yesterday, and then the next day I start at the beginning and I go through to the point at which I stopped at previous days, and each time I do that I see something I don’t like. I see something that doesn’t make sense, something that’s stylistically askew or unclear or needs to be rearranged, so I do a lot of tinkering and tweaking. So every time I would send it to her I’d say, “I made a few more changes, oh, and I didn’t highlight them, I didn’t use Word”—

² Paul K. Longmore and Lauri Umansky, ed., *The New Disability History: American Perspectives* [New York University Press, 2001]

09-00:32:05

Lage: Track changes.

09-00:32:07

Longmore: Yes, tracking, I didn't use it, because I don't use Word so I didn't do that and mostly I'm writing with myself as the only reader and editor, so I wasn't used to doing that, so she'd have to go through the whole thing and this would go on for week after week, and she—

09-00:32:28

Lage: Are you still friends?

09-00:32:30

Longmore: Yeah, we are, yeah, which I think—she—“Oh, man when are you going to be done with it, we'd better get this thing finished, you can't just keep making these tiny changes week after week.” But I did.

09-00:32:43

Lage: Yes.

09-00:32:44

Longmore: We each contributed substantively to that intro, and I think that was a point at which the collaboration really, I thought, worked.

09-00:33:02

Lage: Yes. One of the points that you made in there, or one of you made, you ask the question, “Why has disability been left out of history?” Was that your thinking, her thinking? Or something you—

09-00:33:14

Longmore: I think I wrote those paragraphs. At least the initial draft.

09-00:33:15

Lage: Yes. Is this something you still—still applies? Exis—

09-00:33:25

Longmore: Existential anxiety?

09-00:33:26

Lage: Existential anxiety.

09-00:33:27

Longmore: Yeah—oh, yeah.

09-00:33:30

Lage: Talk about that just a little bit—I found those thoughts—

09-00:33:33

Longmore: Well, that's not an original idea with me. Actually I got, I first got that idea from Harlan Hahn and Harlan's point was the presence of a person with a disability, and there is psychological research to support this, triggers discomfort, anxiety. So the point, applying that to the study of history what we

were trying to say was that people tend to want to avoid looking at disability because it triggers various kinds of anxiety in them about their own—well, it's usually said, their own mortality. I don't think it's their mortality, I think it is their morbidity and fragility.

09-00:34:28

Lage: You use the phrase “subjection to fate.” I like that.

09-00:34:33

Longmore: Oh, yeah, that's another one—and there's a particular American cultural factor, I think, that plays into that, which is that Americans, I mean this is true of moderns in general, but American moderns in particular, that disability exposes the falsity of the notion that you're in control of your own fate, and Americans want to think that they can manage their own destiny.

09-00:35:13

Lage: Well, to a greater extent than Europeans or Asians.

09-00:35:16

Longmore: Than most other, yeah, those people and most other cultures historically, and I think that disability, maybe even more than death, suggests that you're not as in much in control as you want. Now, it's interesting, while you were asking me before we started also about something I'd said to you a long time ago about my differences with the disability rights movement, the response of the disability rights movement has been to say, “Well, the seeming dependency and apparent helplessness of people with disabilities is socially constructed.” People with disabilities could enjoy self-determination if we're guaranteed the tools, the accommodations, the access, the means to direct our own lives, to make our own choices, and that's all true.

I think also, though, that the disability rights movement may have carried that too far because it ends up in a lot of ways masking the actual inherent difficulties and limitations and the real suffering of people with certain kinds of conditions, so what ends up happening with, among disability rights activists is in private they'll talk about the real struggles physically and in public they'll talk about the civil rights issues. Well, we need to talk about the civil rights issues, but I think it's seriously problematic that these two public and private discourses are so separate from one another.

I'll give you an example. I won't name the person. A leading disability rights activist—a number of years ago I was at a rally in UN Plaza downtown, and this person was going to speak, and I hadn't seen this individual in a number of years, and I said, “How are you doing?” And he started telling me about all his health problems, and he was really in bad shape. And then he gets up to the microphone, and he starts talking about, all of this is socially constructed, I mean all his limitations are strictly a matter of things like inaccessibility. And I thought, wait a minute, what about what you just said to me? So I think we understand the reasons that particularly American disabled activists have felt

the necessity of talking in these ways. Probably, well, the certainly unspoken, possibly unconscious, assumption is, we cannot take the risk of talking publicly about these inherent difficulties or this innate suffering in some disabling conditions because if we do, nobody is going to hear what we say politically about prejudice and discrimination and civil rights and access and accommodations. They're just going to—

09-00:39:24

Lage: And ability to do the job.

09-00:39:25

Longmore: And yes, the real and inherent capacity of people with disabilities to make self-determining choices and to be productive and have meaningful lives. They're not going to hear any of that. All they're going to hear is, "I'm suffering. My life, my life is really negative." And their reaction is likely to be, "Well, see, I knew it. I knew that you were less than fully human. I knew that this was really a tremendous tragedy."

09-00:39:56

Lage: And pity and the whole—

09-00:39:58

Longmore: Yes, it would evoke all that pity and then the political message would be lost. I think that's underlying the public silence about what people talk about in private. It's unfortunate, and it may be the case that, and I think it probably is the case, that ours is a culture, modern culture in general, American culture in particular, that is just not mature enough and not reality-oriented enough to grapple with the paradox, but the truth that people may experience real limitation and actual suffering and still be fully human and have meaningful and satisfying lives. I don't think—

09-00:40:59

Lage: And productive.

09-00:41:00

Longmore: And productive lives as well. And I don't think that this society is probably mature enough to be able to handle all that. I would like disability studies to grapple with all of that. I've tried to approach things in this way in the book I'm writing about telethons and disability in American culture so that I can critique both those dominant ways of looking at people with disabilities and also critique the disability rights reactions against the stereotyping and the deeply prejudicial image-making, but I want to critique the disability rights perspective because I don't think it adequately grapples with that other side of disability, so—

09-00:42:00

Lage: It also, I just wonder if politically, does it undercut the fact that people with disabilities often do need extra social supports, money—

09-00:42:16

Longmore:

Well, one of the reactions in criticism of the disability rights movement is the notion that if you want to be equal you can't say you need *special* arrangements, *special* supports, benefits, and that's at the heart of social welfare policy. If you're really disabled, which is to say physically, vocationally, and socially incapacitated, then you're eligible for social welfare benefits, but if you're not physically and critically vocationally and socially incapacitated, then you have no right to those things.

The fact is, the disability rights movement implicitly, though not usually as explicitly as maybe it ought to be, says, well, the only way for people with disabilities to be truly equal socially is if we're allowed to be different in the ways in which we're different. And the only way we can be, well, not all of us, but some of us, can be self-determining and productive and socially integrated, is if we are ensured of these accommodations and assistance and benefits and devices as social rights. Those are pretty radical notions and they challenge deep-rooted traditional and conventional American notions of what constitutes equality. That leads to another, I think—

09-00:44:16

Lage:

Is this something you'd like to see the disability movement incorporate more?

09-00:44:21

Longmore:

Well, I'm not sure it's politically practical. It's certainly not explicit in much of disability rights advocacy now because it wouldn't fly in American political culture. I think one of the shortcomings of the disability rights movement is, we've never had political philosophers who have adequately fashioned an ideology, a philosophy, a theory of disability and disability rights. Now, there are people who've written about these things who are philosophers, but I'm not satisfied with the way they talk about disability. It ends up being, it ends up reinforcing often times, the ideas, well, either that people with disabilities are inherently dependent, or, it propagates implicitly the notion that there's two kinds of people with disabilities: those of us who can make it in the world as it's constituted, with some minor modifications; and people who are so disabled that they couldn't make it under any circumstances and they are inherently dependent and less human.

09-00:45:53

Lage:

Now is this, this dichotomy you've just described, is this part of the discourse in the disability rights movement? Or among—

09-00:46:03

Longmore:

Some, some people have written about it. Yeah, some people have written about it.

09-00:46:07

Lage:

And—people within the movement, political philosophy—

- 09-00:46:12
Longmore: And in disability studies, some people. I mean, um—
- 09-00:46:15
Lage: Name [chuckles]—I mean, that’s something we can talk about {here}.
- 09-00:46:18
Longmore: Well, my colleague at San Francisco State in philosophy, Anita Silvers, has written about disability and dependency in exactly those ways.
- 09-00:46:28
Lage: Yes. And you reject that dichotomy.
- 09-00:46:32
Longmore: Yeah, I do. I do, yeah.
- 09-00:46:33
Lage: You see it more as a continuum? Or—
- 09-00:46:36
Longmore: Well, no, I think that it’s possible, as I think I quoted Carol Gill as saying, “There are lots of ways to be human.” And if there are notions of citizenship or personhood in our culture, or in somebody’s philosophy that perceive certain kinds of people as not fully human, then I think the defect is in the culture and the philosophy, not in those people, in the disabled people.
- 09-00:47:15
Lage: Your critique is as much of, maybe it’s not just American culture, but we’ll say American culture, as of the movement, the disability rights movement.
- 09-00:47:25
Longmore: Well, yeah, I don’t think, well—
- 09-00:47:26
Lage: I mean, I hear the difference.
- 09-00:47:27
Longmore: My hope had been that disability studies would—I think that’s what a lot of us had in mind at the beginning. My hope was that this would be the analytical and intellectual contingent of the movement that would do the kind of research and analysis necessary to formulate an ideology of disability and disability rights. I don’t think that’s happened, at least not to my satisfaction as yet.
- 09-00:48:07
Lage: Now, you’ve had your differences with Lennard Davis, we talked about that last time. Do you like his ideas of normalcy and critique of normalcy?
- 09-00:48:16
Longmore: Well, I have pretty strong disagreements with his perspective on disability.

09-00:48:25

Lage: In general, now.

09-00:48:27

Longmore: Well, in his essay on what he calls “dismodernism,” he essentially erases disability. It comes out of a kind of liberal assimilationism, in which we’re all disabled. He says frankly, at the outset, that he wants to set aside and do away with the notion of disability identity. Well, I think that’s really dangerous, not just at this historical point, but it also fails to acknowledge and grapple with not just prejudice and discrimination against people with disabilities, but the different and positive experiences of people with disabilities. I think it’s disempowering of people with disabilities because it erases what’s distinctive about disability experience.

09-00:49:39

Lage: So you would see a kind of a, not a continuum of people—

09-00:49:47

Longmore: I see Anita Silvers’s view as a kind of conservative assimilationism. I see Lennard Davis’s view as a liberal assimilationism, and neither one of them acknowledges, at least not sufficiently, the reality of difference. It certainly does not affirm it, does not allow for the basis of positive individual identity and community-building among people with disabilities. But I also think that Davis’s work, what he really wants to do is normalcy studies, you know. I think in a subtle way it shifts the focus back away from people with disabilities to nondisabled people. It’s fine to study nondisabled people. I do it all the time and a lot of what I’m talking about in this, in the things that I’ve written, is about people without disabilities, but the ground, the center, the starting point of disability studies, I think, needs to be the experience of people with disabilities.

I am drawing a lot, these days, on the new work in minority identity by a group of scholars, mostly people of color, who are, well, the project started at Cornell University, the Future of Minority Studies Project. I think it has a lot of really valuable implications for disability studies and for disability rights, and it certainly fits in with the minority group model that the disability rights movement with and that disability studies in the U.S. started with—

09-00:51:57

Lage: And you haven’t rejected that model.

09-00:52:02

Longmore: Not at all, no. I—more than ever it makes sense to me. The social model of disability that grew out of the British disability rights movement and is the core, theoretically, of British disability studies has some real valuable merits. They did something that U.S. disability studies did not try to do, which I always thought was a weakness: they distinguished between disability as a socially constructed status and condition, as compared to what they called

impairment—which is a physiological condition. They wanted to distinguish the two. I thought that was a valuable step.

09-00:52:50

Lage: But they acknowledged the impairment part.

09-00:52:53

Longmore: They acknowledged the impairment part. What they didn't acknowledge, and they've been criticized for, by British scholars, is that they didn't acknowledge that impairment itself is in many ways socially constructed, although I don't want to carry that too far, because it's not entirely socially constructed. I mean, the pain in my knee, it may have an element of social construction, in terms of how I perceive it, but it's still a big pain in my knee. I think there are deeper problems that nobody in British or American disability studies has really grappled with in terms of that social model. One of the things that happened was in the 1980s, the U.S. disability studies movement was made up mostly of social scientists and policy people and political advocates, and we were the ones who—we were operating on the basis of a minority group model of disability, which we didn't originate. It came out of the disability rights movement in the U.S., and it made sense politically as well as analytically, because that was the whole framework within the American political culture for dealing with these kinds of issues of prejudice and discrimination.

09-00:54:28

Lage: The civil rights model.

09-00:54:29

Longmore: Civil rights theory was based on the idea of minority groups, and as time has gone on, American understandings of minority status have become more sophisticated and complex. There is not just one kind of minority group, there are many kinds, and we need to flesh out a lot more about what disability minority status is. Well, in the 1990s and since, a lot of those social scientists, unfortunately, exited disability studies, and the humanities people took over, and for some reason they are totally, in most cases, unaware of this history of disability studies in the U.S. and of the minority group model in disability studies and in the disability rights movement, and they've completely embraced the social model.

09-00:55:25

Lage: They've embraced the social model that England has.

09-00:55:28

Longmore: Yeah, out of Britain. Well, the—the social model grew out of the roots of the disability rights movement there, which really drew a lot on trade union Marxism. If American disability rights and disability studies thinking adopted a minority group model, it was to say disability is like race and like gender. The British social model said disability is like class. So there are valuable insights in both ways of approaching things. The limitation is that you also

have to say disability is not like race or gender or class; it's different. It's like them in some ways.

09-00:56:25

Lage: It's like some of them and—

09-00:56:26

Longmore: Yeah, in some ways it's like them, in other ways it's not like them at all.

09-00:56:29

Lage: What's the effect of the social model in Britain in terms of policy, on their disability policy?

09-00:56:37

Longmore: It, in a salutary way, promotes the notion that society constructs disability. So inaccessibility, lack of accommodations, is what really disables people, as they would say, with impairments. I have a couple of problems with the social model in other respects. It defines impairment, the classical social model defines impairment, as physical and physiological limitations. It defines disability as social oppression. I don't find anywhere in that a basis for building a positive individual identity or a disability community. I don't find a basis for pride or for a sense of a commonality that's positive, other than shared oppression.

Likewise, impairment, in viewing disability or in viewing physical condition as a bodily limitation, doesn't account for the total scope of experiences people have. For instance, a lot of deaf people would say, well, no, I don't think of deafness as an impairment. It's a difference physiologically that leads to different ways of communicating. Now, I may not go so far as to agree with them that it's not an impairment at all, but there's a really valuable insight there in the notion that in many respects most disabilities are just different, a different way of being in the world, a different way of experiencing your body, a different way of accessing reality, a different way of operating, that's not inherently inferior. I don't see the social model as offering a way to think about impairment as a subset of a larger category which would be physiological difference that leads to different ways of functioning experiencing reality.

So I think the minority group approach to disability does offer the means, conceptually and analytically, to think about disability experiences, disability identity, disability community, in really positive ways. So instead of just focusing on prejudice and discrimination as the social dimension, we can think about alternative ways of being a part of society, of different values, of a community that shares those values and can offer those ways of looking at the world, looking at society, critiquing society, rebuilding society, building community, experiencing community, all that as things that we can positively offer to the rest of society.

For example, it seems to me the concept of universal design, which is a step beyond accessibility, has really transformative social implications because it really involves not just how you build an environment or fashion a product or an object that people use, it's a way of thinking about what sort of community you want. It's a community that's truly pluralistic, that doesn't just pay lip service to diversity and difference, but plans for them and incorporates them, and integrates as much difference as it can into the way it organizes social spaces. That is, to me, a radically transformative vision of a different kind of society, and the disability rights movement has been propagating those transformative notions. I think the next step would be to incorporate transformative visions like universal design into a more coherent ideology—your red light is flashing, do you want to—

09-01:02:11

Lage: It is—we have about two minutes, but why don't we change now—

09-01:02:15

Longmore: Okay.

09-01:02:16

Lage: Let you stop for a breath here. [chuckling]

[Audiofile 10]

10-00:00:00

Lage: Now we're recording on tape ten. You were just talking about universal design as more than a way of designing, but a whole notion of an ideology—

10-00:00:15

Longmore: Well, if you think about not only universal design but a number of the important concepts that the disability rights movement has invented and introduced, they really have implications well beyond people with disabilities. I mean, they started out as proposed features that would enable the social integration of people with disabilities. As it turns out, they changed the life of non-disabled people as well. So, for example, go to any shopping mall, such as over here at Stonestown Galleria. At the Macy's at the mall, there's the old staircase and then on the other side there's a long ramp. If you position yourself where you can see both the steps and the ramp, you'll see quickly that 90 percent of the pedestrians go down the ramp rather than the steps. It's easier, it's safer, it's more convenient. It's not just people pushing baby strollers or, say, older people who walk a little bit more unsteadily; it's virtually everybody.

A number of years ago in Washington DC, the Metro System there was retrofitted for access, and so they have not only elevators, but they've got flashing lights for deaf people—Gallaudet University is there. They've got audible signals for blind people, they've got bumps on strips at the edge of the platform so that people with visual, vision disabilities know when they're nearing the edge of the platform. United Cerebral Palsy of the Washington

metro area did a study, and they found that all kinds of people, without any of those disabilities, were using those access features, or accommodations, to facilitate their passage through the Metro stations. So it turns out to be advantageous for everyone. So we've reached a point at which we at least have the potential to make an argument that, in fact, all of the features that were originally thought of to accommodate people with disabilities end up helping us build a society that is much more efficient, more comfortable, more integrated, more democratic.

10-00:03:23

Lage: I'm just wondering—I'm seeing a little contradiction, maybe.

10-00:03:28

Longmore: How's that?

10-00:03:29

Lage: With what you said earlier. In objecting to Lennard Davis's idea where he's kind of erasing disability. In a sense—

10-00:03:49

Longmore: Well, I don't think those features erase disability. The people who have mobility, vision, or hearing disabilities still have those. I think it's an environment, a redesigned environment, that allows them to operate in their own way, so it's actually pluralistic. It doesn't erase disability, it accounts for it; it incorporates it into its planning, and into how it allows or enables people to function.

10-00:04:25

Lage: It acknowledges difference without erasing disability.

10-00:04:30

Longmore: Yeah, yeah. And in fact, it affirms difference. I mean, it's essentially saying, well, you don't have to be hearing, or sighted, or a power walker to be able to participate in the community. You can be different in all these ways.

10-00:04:51

Lage: Very interesting. When you talk about the disability rights movement—it just sounds like a tremendous “thing.” [chuckling]

10-00:05:02

Longmore: Yeah.

10-00:05:02

Lage: What do you mean by it, or are there particular organizations that you would include?

10-00:05:06

Longmore: Well, there is no single homogeneous disability rights movement. There really are at least a half dozen movements about disability rights and each one reflects the interests and issues and concerns and needs of a particular

disability constituency, so the deaf community, the organized blind movement, the independent living movement, the psychiatric survivors movement, the learning disabilities movement, the developmental disabilities community—all those are in some ways separate from one another. In the last generation or so, since the mid-1970s, they've allied with one another politically. That's how Section 504 of the 1973 Rehabilitation Act finally got promulgated. That's how the ADA got passed. There has grown up a sense of a kind of universalistic disability set of interests, or, well, common experiences, similar experiences anyway.

10-00:06:29

Lage: Is there cross-disability identity?

10-00:06:31

Longmore: Yes, yes, there's that, but that exists along with these distinctive disability constituencies and distinctive disability identities. And that's not at all unusual. Every one of us has more than one identity—it's just that some of those identities are more salient in some contexts than in others, and so the disability rights movements politically reflects that. There are times at which they align with one another, there are times at which they're in competition, because on the one hand they have different interests. Sometimes they're competing. The Deaf community got very upset with advocates of mainstreaming in schools because they said that it's going to inhibit deaf kids from learning sign language. There's also the fact that funding sources tend to follow diagnostically defined channels, and since the resources are always scarce, there's competition for the resources. I think the amazing thing is that there would be any sense of universal cross-disability connection or identification at all. That historically is very new.

10-00:08:04

Lage: Are there people who have particularly been the ones that you would give credit for helping create this identity? Or was it more circumstance?

10-00:08:13

Longmore: Well, the people who were involved in the American Coalition of Citizens with Disabilities in the mid and late-1970s began to—and even before that leaders from various disability constituencies were getting to know one another and thrashing things out in the annual meetings of the President's Committee for Employment of People with Disabilities in the years before that. Another way in which it's developed is a kind of broadening of some organizations' scope. Independent living centers, originally, were exclusively for people with physical disabilities. Now, they serve people with all kinds of disabilities. I did a workshop on the disability rights movement at one ILC here in the Bay Area a number of years ago and in the course of the discussion, one of the staff people registered a complaint. She had a hidden disability. She was complaining that there was a hierarchy of privilege and of legitimacy—the really authentic people with disabilities were wheelchair riders and people with physical disability. At least, that's what she thought

was the way things operated, whereas, people with non-apparent disabilities like hers were to a degree marginalized; their issues were less attended to, she thought. They were regarded as somehow less authentically disabled. What struck me as historically significant about her complaint was that a generation earlier, the issue wouldn't have come up, because we wouldn't have all been in the same room.

10-00:10:25

Lage: Right, and she might not have acknowledged she had a disability.

10-00:10:29

Longmore: She might not have, but as a part of that center and that community, she was calling upon everybody else to live up to an ideal, a set of values, that she thought we all subscribed to, which was, we may have different physical conditions, different disabilities in that sense, but socially we all have very similar disability experiences, and we all claim to belong to a cross-disability community, a cross-disability movement, and therefore, those who tend to be marginalized, whose disabilities tend to be less regarded, or even devalued, deserve the same kind of commitment from the whole community as those with the most visible disabilities.

I thought that was indicative of a really substantial shift in thinking, at least among activists, and you can still see that. I mean, there's a sense of cross-disability identification that wasn't there a generation ago.

10-00:11:55

Lage: No. Were you involved at all in the road to ADA?

10-00:12:02

Longmore: Oh, a little bit. I—did I even testify? Or did I just attend—Justin Dart [Jr.], who was a major disability rights activist, conducted hearings all over the country, and I went to the one that he held at the Santa Monica Civic Auditorium. I don't recall if I said anything, if I actually testified, but I attended.

10-00:12:36

Lage: Do you think that's had a—I don't mean to move it along, but the impact of ADA, kind of broadly speaking, is this a major shift?

10-00:12:47

Longmore: I think it's had some significant impact, at least in terms of consciousness, and expectations as well. It's changed the values, the perceptions and expectations of a lot of people both with and without disabilities. My favorite illustration of this is in 2000, ADAPT, the militant disability activist group, which had originally had as its focus access to public transportation, renewed that campaign and targeted Greyhound Bus Lines, because Greyhound had gotten itself exempted from the ADA. So this is ten years after the ADA passed, ADAPT members arranged to ride on various Greyhound bus lines on the same day, all over the country. Now these are wheelchair users. There are no

lifts on Greyhound buses, so they did something very risky—they had Greyhound staffers lift them out of their wheelchairs and carry them onto buses and lift their wheelchairs and put them on the buses. Some of these are heavy power wheelchairs, so there's a risk of damage to the chair and injury to the individual, but they did it. I mean, I thought it was very brave that they wanted to dramatize what the problem was and the resistance of Greyhound to accepting riders with mobility disabilities.

Each of the ADAPT Greyhound bus riders kept a diary of their trips, and then ADAPT publicized those. One of them was a young woman, who, as I recall, rode from Dover, Delaware, to Washington DC and back in a day. And she stopped at various terminals and had to be lifted on and off the bus a couple of times. The key moment for me was, after one stop, she was on the bus, and a passenger who had no connection with the demonstration at all, started to talk to her, and he said, "There was some kind of protest last month in Philadelphia about inaccessibility on the buses there." And she said, "Yeah, I was a part of that too." And then he said, and here's the key moment, he said, "Yeah, it's not right. They should make it possible for you to get on the bus." And when I read that I thought, that's what the disability rights movement has accomplished, because that guy years ago would not have expected to see anybody with a disability like hers on a bus or in any public place, and now he assumes that it's not only a natural thing, but it's her right to do it.

10-00:16:13

Lage: So the affirmation of the right is one of the impacts.

10-00:16:19

Longmore: That's a change in American values that we created. We generated that. We changed his mind.

10-00:16:24

Lage: Yes. And do you think you've changed the mind of the next generation [of people with disabilities]? The young people who are coming to college and what they expect as their rights?

10-00:16:33

Longmore: A lot of kids with disabilities that I have taught over the last couple of decades came through a public school system that was changing itself, reforming to integrate kids with disabilities of various kinds, and those kids have expectations now, for at least their education, that they wouldn't have had, that people of my generation had to come to believe we had a right to. I think these younger people expect that their post-educational careers and lives are going to be very much like those of their nondisabled peers, but I think that many of them are going to discover, once they get into the job market and the workplace, that things there have not changed anywhere near as much as the schools have changed, and I think there's going to be a glass-ceiling effect. I'm hoping that that's going to politicize a lot of them—who—

10-00:17:51

Lage: Who may not be politicized.

10-00:17:53

Longmore: Who may not be politicized as yet, in fact, are not. A long time ago, back in the late eighties, I first encountered this. I came up from L.A. to speak at a number of Bay Area schools, and I spoke at Berkeley, at UC Berkeley, to an audience of students with disabilities, and I talked about our responsibilities to other people with disabilities. We got an education. That's a pretty privileged position. Most people with disabilities don't get those opportunities that we've gotten and that obligates us to do something on behalf of other people with disabilities. One young man said, "Well, I've been a pioneer all my life, and I'm kind of tired of doing that."

And I pulled rank on him, I said, "Yeah, well, you got to be a pioneer 'cause people like me were pioneers before you." And he said, "Well, it's like, if we were black and you were black you'd be telling us that you have to go back, we have to go back to the black community and work there." And I said, "If you were black and I were black that's exactly what I've been telling you, I would be telling you, but you're disabled and I'm disabled, and I'm telling you that we have an obligation to other people with disabilities 'cause this is a real privilege that we've gotten this education, and we have a responsibility to use it in ways that are going to open things up for other people with disabilities." So, I mean, that was a good example of a kid who had benefited from the changes but really didn't want to be political.

10-00:19:47

Lage: Yes. Did you convince him?

10-00:19:49

Longmore: I don't know—I've had students here at San Francisco State and students at Stanford before that and students at USC before that who just wanted to live their lives. And I can—

10-00:20:04

Lage: Which is understandable.

10-00:20:06

Longmore: I can understand that perfectly. I am not temperamentally an activist. I just wanted to teach and enjoy my life, have a home and experience things, and I didn't really want to have to be out on some kind of battle line. I don't like confrontations.

10-00:20:33

Lage: Despite having had so many! [chuckling]

10-00:20:37

Longmore: Yeah. [chuckling] Yeah. I'll tell you a story. I was asked to give the charge to the graduating class at Claremont Graduate University where I got my PhD—this was two years ago. And I'm sitting next to a dean of one of the colleges

and she's telling me about her experience—she was asked to take over this deanship of this troubled college where there was a lot of infighting, a lot of factionalism, and she'd been doing it for about four years and she had gotten things straightened out, and I said, "Are you working on any kind of research or publication? Has it left you time to do that?" And she said, "No, I haven't had time. I had started my next book just as I was asked to do the deanship, and it's been on hold ever since, and the result is that I haven't gotten promoted to full professor, and that was my full professor book. And I said, "Wait a second—you straightened out a troubled college. You ought to get promoted just for that!" She said, "Well, Paul, you know that's not the way our business works."

I said, "I know that's not the way it works, but it's the way it ought to work, now here's what you ought to do—you say to them, 'This is not an ultimatum, but I really have to think seriously about my professional future, and I want to be promoted to full professor so maybe I need to not renew this position as dean and go back to my department and finish that book so I can get promoted.' And you don't need to issue it as a—you know, confrontationally or combatively. Just say, 'I've got to think about this.' And then the ball's in their court and they really ought to promote you on that basis." And she said to me, "Were you born an activist!?" And I said, "Not really, I just get pissed off a lot!!" [chuckling] About a year later she sent me an email, and she said she had gotten promoted. [laughs]

10-00:22:56

Lage: Hurray!

10-00:22:57

Longmore: Yeah, without the book. So—

10-00:23:02

Lage: She'd followed your advice, I bet.

10-00:23:03

Longmore: Yeah, yeah. She also was Canadian. She said to me, "You know, I'm Canadian. We're not confrontational." And I said, "You've got to learn to overcome your inner Canadian."

10-00:23:19

Lage: [laughs] That's great. Do you think the disability rights movement goes far enough in challenging the system? The American system, capitalism, and the whole works? I've heard that criticism.

10-00:23:37

Longmore: Yeah, well—just speaking as a historian, apart from whatever political stance I might take —

10-00:23:42

Lage: Well, do it as both.

10-00:23:44

Longmore:

Yeah—the disability rights movements, for the most part, with a few exceptions—I don't mean the movements, I mean a few individuals—the movements in general have been liberal, reformist rather than radical and transformative. They've not fundamentally challenged capitalism or the American system, or even fundamental American values, I think. There are some activists and thinkers who've gone a lot farther with that. It should be said that some people have a kind of rosy, utopian view of what an alternative would be, such as some kind of socialist system, but if you look at most socialist societies, whether you're talking about former Communist states or democratic socialists, or social democratic states, they haven't done any better and in many ways a lot worse, by people with disabilities in those societies, than the U.S. has. I mean, a lot of this stuff, is shaped by cultural values that go even deeper than political ideology and—anyway.

10-00:25:14

Lage:

So maybe it—it's worked as well as it can, by working within the system?

10-00:25:22

Longmore:

Well, if I'm just talking about myself, my own perspective on things, I'm pretty much a dissident, and I think I would be wherever I was. I'm not a utopian at all. I have ideals, but I wouldn't say I'm an idealist, so I find myself pretty much questioning and criticizing most systems that I look at, whether it's political and social and economic systems or theories and ideologies, I find myself skeptical and questioning of them, which makes me pretty useless as an activist and any kind of leader. I mean, it marginalizes me and it makes me an outsider.

10-00:26:23

Lage:

Because you can't commit to the—

10-00:26:25

Longmore:

Well, I'm there on the side—

10-00:26:28

Lage:

The campaign, kind of?

10-00:26:29

Longmore:

I'm there at the margin and I'm saying, "Well, that's good, but it doesn't go far enough." And I say that about most things, not just this system that I'm in, but any other that I might be in.

10-00:26:46

Lage:

And then you also critique the alternative system that might be substituted for it. [chuckling]

10-00:26:51

Longmore:

Sure! Well, you know—I grew up, as I've told you, in a very religious family and an evangelical subculture, and I was a minister's son, and the really liberating thing about that was, I wasn't, and haven't been, intimidated by

authority figures. I think being in the hospital as a kid also helped that, so questioning authority comes pretty naturally.

10-00:27:28

Lage: And your generation also.

10-00:27:30

Longmore: And my generation also, yes, that's true. We were outsiders as evangelicals; I became an outsider as a person with a disability. I not only felt free to ask questions, but I really am deeply suspicious of people with power because of my experiences especially in the hospital. Somebody might claim to have your best interests at heart, but you better look warily at what they're actually doing—and what do they really know? People can tell you, quite authoritatively, what the truth is, whether it's religious or medical truth, but they might be way off base.

So one result is that when it comes to, well, for instance, disability studies, I'm really uneasy with quote unquote theories, analytical concepts that seem to me to quickly ossify into dogma. I'm also worried that any kind of dogma, whether it's academic or religious or political or medical, becomes an easy explanation—an automatic explanation of reality. So instead of thinking, we just plug in this idea, and that distances us even further from the historical and social experiences of real people. It distances us from ourselves, because we tell ourselves all kinds of stories that may really be another kind of dogma. I mean, I worry about, for instance, what I'm saying about myself to you in these interviews.

10-00:30:13

Lage: Wait 'til you see the results!

10-00:30:15

Longmore: Well, I'm probably going to look at them and say, "Yeah, you've been saying that same stuff about yourself for all these years, and is any of that really true?" The book I'm working on, telethons, I made a strategic decision—I'm not sure if it's going to work. I know I could get very harshly criticized and perhaps justifiably—I am so far using hardly any established theoretical apparatus from disability studies or anything else. And the reason is, well, for instance, this book would very easily lend itself, this subject would easily lend itself, to the enormous amount of scholarly work in body studies. I've read some of that stuff, and I find it really troubling when it's applied to people with disabilities, because so much of the stereotyping about people with disabilities has only seen them in terms of their bodies.

So I know that, I'm sure that the body study scholars would say, "Well, that's the point, we're looking at the construction of bodies." And what I want to do is—I don't think of stereotypes, or the prejudices, or the social experiences, particularly, of people with disabilities as just about bodies; there's something more than that. It's about social identities and prescribed social roles and

where you get located in society, where you're allowed to locate yourself or be located. It's about power.

So I made a strategic decision. I thought, you know what I'm writing about in writing about these telethons is layers of images that have been laid on top of people with disabilities—painted over and over again. My dad had a little wooden chair that he'd had since boyhood up until his old age. And every so often, every few years, he would repaint it. So this thing had a red coat, and a green coat, and a black coat, just layers and layers of paint, and unfortunately, the wood that was underneath, which was really nice wood—it was a very sturdy little chair—it got covered over with paint.

So I think the telethon images are like that; I want to strip away and see what's underneath and hopefully get back to people with disabilities themselves and show what's done to them by these layers and layers of images that are put on top of them which are really designed, unconsciously usually, to obscure the reality of the experience of people with disabilities in a society that holds them often in contempt. So I strategically decided I don't want to add more layers. I don't want to add more abstractions of academic concepts that are just going to distance readers even farther from the real experiences of people with disabilities.

10-00:34:13

Lage:

Do most of the scholars who write about people with disabilities using this body theory—do they have disabilities themselves?

10-00:34:24

Longmore:

Some do. Some don't.

10-00:34:25

Lage:

I would find myself very uneasy doing that, because it is sort of depersonalizing and dehumanizing.

10-00:34:40

Longmore:

Yeah, one of the moments that made me decide on this approach and on the issue is I read what's regarded as a very important study about disability in nineteenth century American literature, and all the way through it, this author keeps talking about bodies, talks about blind bodies and deaf bodies—it's all bodies. And I thought, this is just distancing, this is more abstraction.

10-00:35:15

Lage:

Yeah, very.

10-00:35:16

Longmore:

You know—and I felt very alienated from it. I felt personally, as you're saying, dehumanized by it, but I certainly thought it was dehumanizing of the people with disabilities whether they were real life people or fictional characters in stories. And I thought, this just, this is not going to help anybody to get closer to apprehending that historical experience. What I hope with this

telethon book is that if you can strip away all those accretions and abstractions, then we can uncover what's really going on, its really destructive effects, its—well, I think when people read this stuff, it's kind of a distillation of years of watching telethons, so I think a lot of people are really going to be jolted by it, because I'm trying to do this in an unvarnished way. I'm working on the chapter right now on children with disabilities in the telethon and some of the stuff, it's just incredible.

10-00:37:08

Lage: Are you talking about the actual children who took part in them? Or—

10-00:37:14

Longmore: The way they're portrayed, the way they're talked about, and then their own voices, what some of them say. I'll just give you one example. On one telethon, a father comes on, he talks about his, I guess she's twelve at the time, so she's just on the verge of being a teen. He says on national television, "This is a kid who's never going to be asked out on a date, never going to be asked to the senior prom, never going to be asked to have pizza on a Friday night with a friend." And I thought, his daughter heard this! And he's clueless—she might not get asked out on a date or to the senior prom or to have pizza, but he's clueless as to the reasons. He doesn't say anything, and the telethon doesn't say anything about, well, disabled girls and women are really devalued in this culture that places so much emphasis on a certain kind of beauty. That's why she's not going to get asked out, and what do we do about that? And I thought, even if you don't understand, what a thing to say on national TV about your own kid. I mean, that shows you how much he had been taught to devalue his own daughter.

10-00:38:49

Lage: Yes. And then she probably absorbed it all herself.

10-00:38:53

Longmore: Of course she did, yeah.

10-00:38:56

Lage: We talked a lot about physician-assisted suicide, kind of through the eighties. We didn't talk about anything you might have been involved with relating to Dr. Kevorkian or later things. Do you want to go back to that?

10-00:39:19

Longmore: I got a call—This is in the late eighties.

10-00:39:22

Lage: Yes. We did the Rivlin and McAfee cases.

10-00:39:26

Longmore: Yeah. I guess it was that same year, 1989. I got a call from a producer at *Crossfire* one day. I think this was probably that fall after, or maybe that

summer, I forget when, but they said, “You know, we’d like you to come on opposite Dr. Kevorkian on *Crossfire*.” And I said, “No.” And the reason I said no was—it had nothing to do with the issue or with Kevorkian, it had to do with *Crossfire*. Because I thought, this is one of the major mechanisms by which the debasement of American public discourse is taking place. I mean, it’s just shouting. And it’s just gotten worse in the almost twenty years since then, so I refused to do that. Well, what happened since then.

10-00:40:46

Lage: Were you at all involved in the activist groups? Like Not Dead Yet or ADAPT?

10-00:40:54

Longmore: I had a connection. I’ve had a connection with Not Dead Yet, more so in the past, less so in recent years. I used to speak a lot in the early nineties at conferences on assisted suicide. It’s interesting—the proponents of legalization of assisted suicide, I think, wanted at least to seem balanced and fair, hearing the other side, and so I got invited to do a lot of things and to speak at a lot of these conferences. I was usually the only voice against it. One of the few, anyway. And they had people there that they were trying to win over at these various gatherings, and I’d like to think they stopped inviting me because there were too many people who said, “Hmm, he has a point.” Anyway, I stopped getting invited. And I got involved at various times in opposing ballot initiatives. There was one in what, ’93, or ’92, I guess, on the California ballot.

10-00:42:18

Lage: Yes. Yes, and there was the Oregon initiative.

10-00:42:23

Longmore: Yeah. I wasn’t involved with that; I only was involved with stuff here in California. There was a bill in ’99-2000 that I helped work against. And then another one last year, which is probably going to be reintroduced this coming year in the California legislature. I was involved in the fight against those—I mean not in a prominent way, just one of the people who was active.

10-00:42:54

Lage: Yes. Did you get involved in the Terri Schiavo case?

10-00:42:57

Longmore: No, I didn’t.

10-00:42:58

Lage: Did that speak to you?

10-00:43:00

Longmore: I find that case and similar cases problematic. For one thing, I think this is another example of how disability activists have really done a poor job of figuring out just what they think disability is.

10-00:43:23

Lage: Yes. Oh, that's interesting.

10-00:43:26

Longmore: They end up lumping together all kinds of experiences, all kinds of conditions, that—I'm not saying they're not all disability. I'm saying, you'd better figure out in what way all these things are disability. I mean, what do they have in common?

10-00:43:47

Lage: Right—well, what things do you—

10-00:43:49

Longmore: Well, for instance, Lennard Davis and other people have criticized disability activists for identifying terminally ill people as disabled, and I think there's a good point there, in that the activists have not explained very well, in what sense somebody who's terminally ill is a person with a disability. And Davis and others have said, "Well, disability in terminal illness is not at all like, say, a chronic condition that somebody has for years. This is a person who's going to die in a matter of months." And there's a valid point there, too. And the activists have not adequately differentiated those different kinds of disability experiences. Nonetheless, Davis and others, I think, are wrong, are misperceiving the importance of disability in the experience of terminal illness because they don't understand how it's really operating. They're saying, "Look, somebody who becomes disabled when they're dying—they're not going to get rehabilitated."

Well, rehabilitation isn't the point. The point is that they go into the experience of becoming disabled, and they perceive it as humiliating dependency. In other words, the devaluing prejudices that they've been imbued with and that the society imposes on anyone who's physically dependent because of any medical condition—that comes into play then, and so they say, "I can't stand the degradation of disability and dependency and I'd rather be dead, so I want to speed up my dying. I want to end it now. I'm a burden to my family. I'm not fully human." Those are all disability prejudices. They just operate in a somewhat different way in terminal illness. I don't think that disability activists have been very adept, not ADAPT, adept at explaining that, so I have that difficulty.

10-00:46:25

Lage: And the Schiavo case is different yet, because she wasn't capable even of experiencing those feelings.

10-00:46:33

Longmore: Well, I have a hard time saying that somebody who is PVS or comatose or minimally conscious, or whatever the term is that they want to apply—there were disputes about what her exact status was—I have a little bit of difficulty just automatically labeling somebody as disabled and then lumping her together with people with all kinds of other disability experiences. One of the

motivations for that identification of her as disabled was that a lot of people who were saying it are very deeply involved with people with cognitive disabilities, who are regarded as mentally diminished, and there is a tremendous amount of contempt for people with those disabilities. Some of them are closely associated with people with autism. I still think there needs to be a distinction made—just for the purposes of precision and understanding. I'm not saying that she should have been starved to death. I don't mean that at all. I think there needs to be more careful thinking about why we get into those kinds of cases if we do. I didn't get involved in it because I was, frankly, troubled and confused about exactly what I thought and think.

10-00:48:31

Lage:

Interesting. It does seem of a different order. Now, I brought this up a few times and you haven't been too interested, but I want to ask you to apply some of the thinking on the right-to-die and physician-assisted suicide issues to the idea of selective abortion and the idea of genetic technologies which may screen out disability from the human condition. Do you have some thoughts about that?

10-00:49:09

Longmore:

Yes, but I'm not confident that they are informed enough, and this is a terrible confession, after all these years, that I haven't thought through these things enough. I find it interesting and a bit troubling that many disabled activists will say, I'm pro-choice, but it's wrong to have an abortion on the basis of disability. That doesn't make a lot of sense to me. I mean, I understand the reasoning—there's a lot of prejudice, I mean, people don't want to have a kid with a disability, and yet, if you're saying you're pro-choice, and part of the basis of this is, well, this is a woman's own body and that's not a person—well, then I don't see how, I mean, it's kind of hard to criticize somebody for the reasons they choose to have an abortion. It's troubling that some people in many countries have abortions as a means of sex selection, but it's based on another kind of prejudice, but I'm not—

10-00:50:41

Lage:

Well, some people are saying we have to have some guidelines on reasons for abortion—even people who consider themselves pro-choice, when they see it as a mostly eugenic move.

10-00:50:58

Longmore:

Yeah.

10-00:51:00

Lage:

But there again these are difficult issues. Then, I'll just ask about one more recent thing—the big brouhaha when Michael J. Fox did an ad for stem cell research. Did that have a little bit of the overtones of the telethon? I mean, how is it different from—

10-00:51:32

Longmore: Well, I suppose it had similar elements in that he's talking about relieving suffering, and I mean, I don't think there's any question that he's suffering. I have a neighbor who has Parkinson's—that's a really serious condition. What troubles disability activists is that it feeds into the notion that your life is ruined because of this condition and you can't have meaningful relationships or meaning in any way. I think this is one of those areas in which our thinking about various kinds of disability experiences is not yet adequate to the complexity of those experiences. How do you make the case that we support medical research to relieve conditions that really do involve suffering—

10-00:52:55

Lage: Yes. Or cure, cure—

10-00:52:57

Longmore: —or that may be, that may be fatal.

10-00:52:57

Lage: —not really relieve, but cure.

10-00:52:59

Longmore: Well, relieve.

10-00:53:00

Lage: In the case of the stem cell.

10-00:53:01

Longmore: Well, when I say relieve I was including cure as one possibility, although in a lot of diseases there aren't cures. I mean, what gets developed is not a cure. It's either a prevention or some kind of relief, some kind of amelioration, but it's not a cure. I mean, not that many things get cured.

10-00:53:26

Lage: But I think the way that the stem cell [research initiative], at least in California, and elsewhere, has been sold is that we're going to cure.

10-00:53:36

Longmore: Yeah, I know, but that's *always* the message. That's the message on the telethons.

10-00:53:40

Lage: Yeah.

10-00:53:40

Longmore: In other words—cure is just around the corner.

10-00:53:41

Lage: That's why I think it has some correspondence.

10-00:53:43

Longmore: And that was the Christopher Reeve pitch and all that experimentation was part of what killed him.

10-00:53:49

Lage: Really.

10-00:53:50

Longmore: Yeah. So I'm told by people in the know. The cures are just around the corner always and cures are going to solve everything—and cures are not that frequent. It's either something that prevents the thing from happening in the first place, or it relieves it once you've got it, but it doesn't necessarily go away completely.

10-00:54:21

Lage: And then I've heard people, in fact, in discussing the stem cell issue saying, "But they haven't asked us, maybe we don't want to be cured."

10-00:54:36

Longmore: Well, then, I guess you don't have to get treatment.

10-00:54:39

Lage: Right.

10-00:54:45

Longmore: I don't really have an awful lot to say about that. I'm sorry, I'm just—

10-00:54:49

Lage: No, that's okay, I can't ask you to talk about something you haven't—. This is neither here nor there, but I was really surprised to hear an opinion piece on NPR the other day about Alzheimer's disease, saying we're putting much too much into *cure* and we should put more into *care* for this disease that's simply a normal—I think they removed the word disease—this condition that's simply a normal part of aging.

10-00:55:18

Longmore: Well, I don't think it's a normal part of aging.

10-00:55:20

Lage: That seemed like a very big shift.

10-00:55:25

Longmore: Well, you know, that's come up in other crusades against particular diseases. One of the criticisms of the March of Dimes was that it put too much money into patient care and not enough into cure research or prevention research—it was prevention research—because they spent a lot of money on taking care of people who got polio, and some of the critics said, "No you need to put a lot more of the dollars into medical research to stop this."

10-00:55:58

Lage: Of course, that worked.

10-00:56:03

Longmore: Yeah. But they didn't follow that criticism. They still, while they had all that money, they still did spend a lot taking care of people who had gotten polio.

10-00:56:20

Lage: Well, what have we missed, Paul, in this long discussion we've had?

10-00:56:24

Longmore: Gee—

10-00:56:25

Lage: It will come to your mind, maybe when you read the transcript.

10-00:56:28

Longmore: Yeah, maybe we'll have to get another tape! [chuckling] I don't know.

10-00:56:34

Lage: Anyway, I think it's been great.

10-00:56:36

Longmore: I've enjoyed talking with you.

10-00:56:38

Lage: I appreciate that you've given me this much time.

10-00:56:41

Longmore: Thank you.

[End of Interview]