

Regional Oral History Office
The Bancroft Library

University of California
Berkeley, California

Disability Rights and Independent Living Movement Oral History Project

Adrienne Asch

DISABILITY SCHOLAR AND ADVOCATE, PROFESSOR OF BIOETHICS

Interviews conducted by
Ann Lage
in 2007

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Adrienne Asch, June 2007
Photo courtesy of Ann Lage

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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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The Bancroft Library

University of California, Berkeley
August 2007

Interview History—Adrienne Asch

Adrienne Asch, professor and director of the Center for Ethics at Yeshiva University, was interviewed for the Disability Rights and Independent Living Movement oral history project to document her contributions for more than three decades as an activist and scholar. She has had an important role as advocate and activist on disability issues in New York and nationally. Her scholarly work is broadly focused on the ethical, political, psychological, and social implications of human reproduction and the family, to which she contributes a nuanced disability perspective.

Blind from birth, she was raised in New Jersey, where she attended public schools and was fully mainstreamed by the fourth grade. Without negative stereotypes of blindness or a sense of limited life possibilities, she was not exposed to experiences of substantial discrimination until she had completed Swarthmore College and began a job search in New York City in 1969. In the early seventies, she joined the National Federation of the Blind and Disabled in Action, picketed for disability rights, and took a leading role in lobbying the state of New York for legislation to extend civil rights to people with disabilities. From 1974 to 1985 she helped enforce the new legislation as a human rights specialist with the New York State Division of Human Rights. As she relates in the oral history, her commitment to disability rights has always been part of a broader interest in civil rights for all.

Asch earned her doctorate in social psychology from Columbia in 1992, focusing on human reproductive issues, and has been a distinguished scholar and teacher of bioethics and the politics of human reproduction at Wellesley College and Yeshiva University, where she now holds a joint position as professor of bioethics and professor of family and social medicine at the Albert Einstein College of Medicine.

Her oral history is valuable not only as an account of her distinguished scholarly career and contributions to the disability movement, but also for her candid reflections on a diverse range of issues. She discusses the interaction of the National Federation of the Blind with the disability rights movement, and explores tensions within the Society for Disability Studies, where she served as president from 1996 to 1998. She recounts her many interactions with bioethicists in many settings over valuing the life of people with disabilities. She reflects on the relationship between the personal and the public life of an advocate and scholar, and she examines her multiple identities and objections to identity “boxes.” Reluctant to provide “the disability perspective,” she nonetheless has often been called upon to bring a disability perspective to bear on a multiplicity of issues, from stem cell research to prenatal testing and selective abortion to end-of-life issues.

Adrienne Asch was interviewed during three interview sessions at her home and her office in New York City in June 2007. The transcription was audit/edited by the interviewer and reviewed by Professor Asch, who made only a few changes to a brief section of the transcript.

The oral history with Adrienne Asch 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

December 10, 2008

Begin Audio File 1 asch_adrienne1_06-19-07.mp3

01-00:00:08

Lage: That should be enough silence.

01-00:00:10

Asch: Well, in New York, you don't ever get quite total silence, unless we closed the windows and turned the air conditioner on.

01-00:00:17

Lage: I think we want the background noise. I can hear children out there, a little bit of road noise. Today is June 19, 2007, and I am Ann Lage, interviewing Adrienne Asch for the Regional Oral History Office project on the disability rights movement. As I promised, we're starting out with the most basic of questions, which is tell me when and where you were born.

01-00:01:02

Asch: I was born here in New York at a hospital that doesn't exist any more, in Manhattan, in September of 1946, and I lived in New York until I was five, and then my parents and I did what a lot of parents do, and moved out of New York, and moved to the suburbs.

01-00:01:31

Lage: Was there a reason for that?

01-00:01:33

Asch: There were a couple of reasons. I mean, you're probably my age or a little older, or maybe a little younger, but anyway, a lot of parents on the GI Bill—men on the GI Bill—got to buy homes that they wouldn't have been able to buy, so my father, who had been in the war, you know, wanted to move to the suburbs and buy a little house. The reason they moved to New Jersey, though, was actually related to the fact that I'm blind, because New Jersey was one of the first states, along with Oregon and California, to routinely let kids who were blind go to their neighborhood school. That was viewed by my parents as very important, and I'm glad that they did that. So, then, we lived—I, and then my sister and brother, when they were born—we lived in a small town called Ramsey from—I mean, my mother lived there from 1951 until she died in 2001.

01-00:02:52

Lage: And where is Ramsey, in relation to New York?

01-00:02:55

Asch: Ramsey's about forty-five minutes from here, if you go across the George Washington Bridge, Route 46 to Route 17—it's in Bergen County. It's a small kind of lower middle class—well, now it might be middle middle or upper middle class, but when my parents moved there, it was a kind of small, working class, lower middle class town in Bergen County, which is a quite populous and actually pretty well-to-do county, but Ramsey wasn't, and that

was partly why they moved there. I mean, they could afford it. And my father's sister also lived there, so they knew about it.

01-00:03:46

Lage:

Well, tell me more about the family you were born into—what your parents did for a living, what their backgrounds were.

01-00:04:00

Asch:

My mother didn't work when I was growing up. Didn't work, actually—she had worked during the war for the War Manpower Commission, doing some sort of secretarial level work. She and my father were born here, and their parents were born here. They lived in New York. Their parents—I don't think any of their parents finished high school. I'm not absolutely sure about that. My parents did finish high school, and my mother and father each had a year or a year and a half of college, maybe. My mother—you know, my mother did what women did in the fifties. They stayed home, and took care of their children. My father had a job doing a variety of sales things, first for a little company, then was in business for himself, packaging things and selling them, but my father was actually a very important influence in my life. One of the most important.

Really, well, my father, you can learn a lot about my father by a couple of things. He described his business as, "The thing that's wrong with America is that America buys what I sell." He had a wicked sense of humor, and appreciated the absurd in life, and would have been much better as a diplomat, or a youth worker, or a social worker, or something, and so a lot of his non-work time was spent being those things. It's not really good to define him, he never defined himself, I think, by what he did. He was a very unusual man for a man of the fifties. I mean, he worked long hours, and he did travel, and so they had a pretty gender stereotyped, sex stereotyped marriage, in a way, but my father really was defined in his own mind by being a son, and a brother, and a father, and a cousin, and an uncle.

01-00:07:02

Lage:

So, very much a family-oriented man?

01-00:07:03

Asch:

He was very much a family person, and a community person. He really took enormous joy in getting to know people. I mean, it's what made him a pretty good sales person, I think, but what he really liked—he was very proud of the fact that when he ran for this school board in Ramsey as a Democrat, which was a quite Republican town, he got the eighteen-year-old vote. And he got the eighteen-year-old vote because everybody, every one of his children's friends really loved him, and thought he was... And one of things that I'm proudest of about my father is that two of my best friends from high school asked him to write them letters of recommendation for major things, one for CO status during the Vietnam War, and one, a Danforth application. Now, I can't say that my father actually wrote those letters, and I don't know that he

did. I hope he did. He was not always the most self-disciplined person, but he was really respected and revered, and I think deservedly so, by many people, for being a thoughtful, smart, funny, kind, sensible, adventurous person.

01-00:08:45

Lage: Was he a joiner? Did he belong to organizations, or groups, or --

01-00:08:48

Asch: Well, the main group he belonged to was working for the Jewish community in Ramsey. There wasn't much of a Jewish community, an organized Jewish community, and he was involved in creating a synagogue and a Hebrew school for his kids, and getting itinerant rabbis to come do services, and things like that. He joined the Republican Party so he could war from within. My mother joined the Democratic Party and was a poll watcher. I don't know that he joined any other particular organizations. Well, he was involved with the UN later in his life, the last fifteen, twenty years, doing kind of business things. Actually, I don't really know what he did. United Towns. It was not quite city to city, but it was helping—well, I don't know. He loved travel, and he loved languages, and he liked the opportunity to—and he certainly believed in the UN, and believed in—like, teaching. He never actually got to do this, but his plan was that some day he was going to go around to high schools and teach kids about the Holocaust.

01-00:10:42

Lage: Were you close? Did you have a lot of conversations with your father, or was he more of a major influence by example, or by sort of a mentoring relationship?

01-00:10:52

Asch: Oh, he was a very involved father. He really liked being a father. He liked playing with kids, he liked playing with his kids, he liked teaching us, so he did all kinds of things with us.

01-00:11:27

Lage: And your siblings? How old were your—how much younger?

01-00:11:31

Asch: I'm six and a half years older than my sister Susan, and ten years older than Carl.

01-00:11:36

Lage: So, you was spread out. Tell me your father's name, and your mother's name.

01-00:11:45

Asch: My father's name is Julian—was Julian. My mother's name was Ruth.

01-00:11:57

Lage: Did they have immigrant backgrounds? You said both their parents had been born here.

01-00:12:02

Asch: Well, I mean their grandparents—three of their four grandparents were from either Germany or Eastern Europe. One of my father's grandparents was born in Pennsylvania somewhere.

01-00:12:19

Lage: And you were born what year?

01-00:12:21

Asch: 1946. And my father was born in 1919, and my mother was born in 1922. So they came from kind of lower middle class Jewish backgrounds, not enormously observant in any sense, but very aware of being Jewish. That was a very defining part of who they were.

01-00:12:51

Lage: And wanting you brought up in a Jewish community, it sounds like, with the religious --

01-00:12:55

Asch: Well, wanting us brought up as Jews. If they'd wanted us brought up in a Jewish community, they would never have moved to Ramsey.

01-00:13:02

Lage: That was not a --

01-00:13:03

Asch: No. I mean, they worked to create a Jewish community within a non-Jewish town. I think my father in some ways liked the nonconformity of being a Jew in a non-Jewish town, and a Democrat in a Republican town.

01-00:13:21

Lage: That's interesting, that he would like that challenge.

01-00:13:23

Asch: I think it gave him a lot of amusement. Yes, well, I think he had a great sense of humor about it. He had made various friends during World War II, when he was in the army, and one of them was from Yugoslavia. He continued writing to the European friends all his life, and I think he loved the idea that the FBI was checking his mail. I'm not sure it was, but I think he hoped it was. It may have been. We actually did have some weird week, where this strange woman named [in an accent] Dr. Stroboya, when I was twelve, came to do something at the UN for a week, and stayed in our house. We never quite knew who sent her, but my father suspected that she was a spy to see exactly what my father's or his friend's sympathies were.

01-00:14:16

Lage: How interesting. But you're not sure how she—he must have invited her to stay.

01-00:14:21

Asch:

Well, I'm sure he invited her to stay. He invited all kinds of people to stay. But I think his friend Ronco sent her, or—I never got the story. But we had all kinds of people staying at our house. Friends of friends, and children's friends, children who needed a place to stay when they had summer jobs and couldn't drive wherever it was they had to go, and they could walk from our house, and people who had crummy relationships with their parents, and needed a kind of sane place to go.

01-00:15:01

Lage:

Oh, that's a good clue, I think, somehow, to the type of family you must have had—a very embracing family, it sounds like.

01-00:15:10

Asch:

Yeah, it was. I mean, I think. I have lots of stories about my father. He was an amazing—and my mother, too, but she was a much more power behind the throne kind of person, and he was a very charismatic person. But my father was an enormous—we had conversations in our house all the time. I mean, the *Brown vs. Board of Ed* decision in 1954 when I was seven and a half—I was very aware of that decision. I mean, I remember things about the McCarthy hearings, when my mother would help me with my homework; she was watching the McCarthy hearings, and I remember when Julius and Ethel Rosenberg were executed, and I was frightened of the electric chair. I remember the Checkers speech. I remember my parents explaining to me that Tricky Dick Nixon was a really bad man.

01-00:16:12

Lage:

Was the Holocaust a big presence? Was that discussed?

01-00:16:16

Asch:

Oh, yeah. The first political thing I ever learned was about Hitler, and Germany, and how Hitler killed all the Jews, and I think I knew that when I was four or five. I mean, not in any particularly scary way. I don't know exactly. It was just one of those things I learned. You couldn't be a Jew in post-Holocaust America without knowing about the Holocaust. I mean, you grew up, you knew about the Holocaust, you knew about Israel. But also, because my father was so interested in foreign countries, I mean, I remember learning about India and Nehru, and I started really paying attention to current events very early. By sixth and seventh grade, I was paying a lot of attention to current events, and reading the *New York Times*, and listening to the radio, and watching—you know, *Meet the Press* or whatever those TV news things were.

01-00:17:32

Lage:

Was the civil rights movement—you mentioned *Brown vs. Board of Education*. Now, how old were you when --

01-00:17:42

Asch:

Seven and a half.

01-00:17:42

Lage: Yeah. That, and then --

01-00:17:45

Asch: Well, and certainly—I mean, in 1963, I wanted to go on the march. My parents wouldn't let me. I was really mad at them. And I don't really know why they wouldn't. I think they—I don't know. I guess they got nervous. Knew what was going to happen, or something, but anyway, they wouldn't let me go. But—

01-00:18:20

Lage: They were supportive, it sounds like.

01-00:18:21

Asch: Oh, yeah. Oh, yeah.

01-00:18:22

Lage: --of the idea. Okay. I wonder about family experience with disability or blindness. Was there a—

01-00:18:34

Asch: Not really. I mean, they didn't have any prior experience in particular. My father and mother, when they realized I was blind, which was—well, I was born premature, as many—there were a whole raft of kids who were born with what was called retinopathy of prematurity. You may know this already. I was born ten weeks premature, and I was very teeny. I was two pounds, and I had to stay in the hospital until I was five pounds, which was about two and a half months. At the time, they didn't know why I was blind, and they didn't really figure it out for many years. The theory was that the kids had gotten too much oxygen in the incubators, which may be right, or may not. Some people think that's actually not the case anymore. But anyway, whatever it was.

When my parents found out I was blind—which I guess they did when I was six months, or nine months old, or something—they went out and talked to The Lighthouse in New York, and the New York State Commission for the Blind, and I don't know what all. And my father went and arranged to have some conversation with some guy who was Jewish and who was blind, and just sort of find out what he could expect, and he really—I remember it was actually kind of—he met this guy, and he didn't like him. He thought he was a really nasty, obnoxious person, which he was. I mean, I met him later, and I completely concurred.

I think my mother was pretty freaked out for a while, and then calmed down, and my father—I mean, freaked out—my mother—Susan and Carl would say that our mother really didn't love being a mother in some ways. I mean, she wasn't a natural mother. She wasn't a naturally spontaneous, affectionate, warm person. She didn't love little babies. She liked grownups. She liked men. She liked women. She liked talking to people. So she liked kids when they could talk to her, and in some ways, I think she had kids because our father

wanted kids. I don't mean that she didn't want to be a mother. I don't think that's right. But I don't think she... I was born only nine months after they were married, and I think she got pregnant sooner than she probably wanted in the first place, and then I was premature, and then I was blind, and I think that she would have preferred just having more time with my father before she had kids.

01-00:22:12

Lage:

Did she ever have this discussion with you, or you're --

01-00:22:17

Asch:

No, not exactly. This is partly what Susan and Carl and I all think.

01-00:22:30

Lage:

But you say she was sort of freaked out by it, and your dad --

01-00:22:33

Asch:

Well, she was freaked out for a bit. I mean, she was scared, and didn't know what she was going to do, or how to deal with it. You know, my father—I'm sure he was upset, too, but not very—I mean, by the time I was at all conscious of such things, whatever freaked-outness was completely not evident. I think they were very interested in just figuring out how to have a life, so I learned how to do things, and my father—because he was a very playful and adventurous person—I think found the whole thing kind of interesting. Like, "Okay. I don't know what it means to have a blind child, but I—" I mean, this I do remember, his saying that he didn't know what it meant to have a child until he had one, so he did all his learning about having a child from being a father, and having a blind child was just another thing to learn.

01-00:23:58

Lage:

Were they more protective of you, do you think, than they were of the other children?

01-00:24:01

Asch:

No, I don't. No, and in fact—I mean, I'm sure they were about some things, but they weren't about very much, and I hated anything like that from very, very, very, very early, so even if they had wanted to be, they would have gotten a lot of opposition. But no, I don't think they were. I mean, I found I wasn't—being blind wasn't very important to me, except if people treated me badly, and I think that's because it wasn't very important to my parents unless there was a problem. I mean, I think their attitude was everything's going to be fine, unless we find out that it isn't, and then we'll solve it.

So when I started learning to read when I was six, my father would go get Braille books from the library for the blind, because I really liked reading, and my father loved geography, and loved countries, and so in addition to teaching me the capitals of the world, and all this kind of stuff, he got maps and put plastic paint on the maps, so I could learn where the countries were. And I think he liked a lot, sort of figuring out, and my mother, too. My mother

taught me how to knit when I was quite young, because she liked knitting. They got a Scrabble set—they persuaded the Scrabble company to make a Braille Scrabble game, because they wanted me to play Scrabble. They got, you know, Braille games of chess, and dominos, and checkers. I remember when I was eight getting a pogo stick. We had a yard, and a long driveway, and my father said that he was going to put a little rock at the bottom of the driveway, so that I would know when to stop using the pogo stick, and not go into the street, but then he saw that I could tell where the bottom of the driveway was, so he didn't put the rock there. He was very good at paying attention to what I needed, and not giving me more than I needed.

01-00:26:57

Lage: He kind of learned from you, it sounds like, in some ways—by observing.

01-00:27:02

Asch: Right. And, I think, tried very hard not to have assumptions of either what I could do or what I couldn't do, and to sort of figure I could do whatever I wanted until we found out I couldn't.

01-00:27:17

Lage: Was there any other medical or social service support system?

01-00:27:23

Asch: The New Jersey Commission for the Blind—they learned when I was very little that New Jersey would let me go to public school in my neighborhood, and the New Jersey Commission for the Blind had a very good program at the time of counselors and itinerant teachers to come out to the neighborhood school to teach things, and work with parents, and work as a liaison between the school, and the kid, and the parents, and stuff like that.

01-00:27:54

Lage: And was that helpful?

01-00:27:55

Asch: It was mostly helpful, although—I mean, it was much more helpful than not, and I also went to a camp for blind kids in New Jersey. But I think the thing that was good about my parents' attitude toward the social service system was that they appreciated it but were kind of irreverent about it. I mean, if it was useful, they used it, and if they thought—I mean, my father said that they got told, or my mother said, I don't remember which of them told me this story—when I was very little [they were told] that blind kids never crawled, but I did crawl, and so I think they learned very early that they couldn't believe what professionals said.

01-00:28:42

Lage: And they seemed to have that attitude in general, towards society and its structures, as you described them.

01-00:28:49

Asch:

Yeah, my sister actually—when my father died, it was very interesting. Susan, who was by far the most conventional person in our whole family, had a song that to her embodied our father. It's called "The Greatest Love of All." I forget who sang it, Carole King, or Bette Midler, or I don't know who sang it. One of the things that she said about him—one of the things about the song that she liked was it said something like, "Everybody looking for a hero, I never found anyone I could look up to, I had to believe in me." And I think she felt—and I think it's true—and then there's a line, "If I fail, if I succeed, at least I'll live as I believe." I think that was true. And my father made some terrible mistakes in his life, and had some sad reversals, and didn't handle some things as well as he would have liked, but he lived the way he believed he should live.

01-00:30:10

Lage:

Were these business-related things?

01-00:30:11

Asch:

Yeah. Yeah. He was a terrible manager, and his little company failed, and it failed because he didn't manage it very well. That was in 1985, and I think he struggled a lot trying to keep this company together, and not let anybody know how badly he was doing, and was very ashamed, and all kinds of things. But the more important point here is I think he taught us to live as we believed, because he lived as he believed. He tried to take the consequences for the things that didn't work, but he lived the way he thought he should live, and I'm really proud of that.

01-00:31:06

Lage:

He sounds like a wonderful man.

01-00:31:08

Asch:

He was a remarkable man.

01-00:31:09

Lage:

And a very fine type of father to have.

01-00:31:13

Asch:

He was a great father. He was a great father to have, and I think had a really profound effect on how I think about lots of things, probably some bad, but a lot good. I mean, in terms of disability—actually, here's not a disability story, but a thinking story. When I was ten—I don't even know if this is accurate—he was trying to explain to me how newspapers slanted the news, which I think was a kind of interesting thing to talk to your ten-year-old daughter about, anyway. But he said, "The Salk vaccine is a big deal, and it's page one on every newspaper, but it's not page one in *Christian Science Monitor*, because Christian Scientists aren't interested in medicine." Now, I don't even know if that's accurate. I mean, if we went back and looked at the *Christian Science Monitor* the day the Salk vaccine was discovered, he might be wrong, but it was a great example to explain to a kid not to take everything for granted—not to assume things.

01-00:32:40

Lage: And not to trust authority figures, maybe.

01-00:32:42

Asch: Right.

01-00:32:50

Lage: Did he have similar stories regarding disability or blindness?

01-00:32:53

Asch: Well, not similar stories, but he had a very --

01-00:32:55

Lage: Or similar lessons, maybe?

01-00:32:57

Asch: Well, different. When I was ten, and I didn't have as many friends as I wanted in fifth grade, he said, "You know, you can't wait for people; you have to go more than halfway to make friends." And that was partly a comment about how people viewed blindness, but it was also partly a comment about the world. If you want to have a friend, you have to be a friend, and Susan and Carl are, just as much as I am, people who when they want to make friends, they go out and do it. Even if we'd sometimes like people to come to us, we don't wait, and that might be good or bad, but we don't. I mean, there may be a certain kind of insecurity in that, that if we don't work at it, they won't, but there's also a kind of assertiveness about it. You're not invited to the movies? Well, then call somebody up and invite them.

Actually, this to me is very funny. Carl and I had a conversation in 1978, so I was thirty-two and Carl was twenty-two, and we were just having some conversation about our parents, or about life, or whatever. I remember saying, "I'd come home from school, and I'd be really upset about how something happened, and I'd talk to Mommy, and Mommy would say, 'Oh, you know, it's so sad, and the teachers aren't being nice to you, and the kids aren't being nice to you, and you have to realize they're just being stupid.'" And I found that really vacuous. Anyway, and I said, "Then I'd tell Daddy the same story, and he'd say, 'Well, let's think about it. What could you do to solve this problem? How are you contributing to what's going on? What could you do differently?'" And I said I really loved that. I said I really hated what Mommy did, and I really loved what Daddy did. And Carl said, "Yeah, I know. They did the same thing, and I hated what Daddy did, and I loved what Mommy did." So, we had completely identical views of how our parents behaved, and completely opposite responses. I found my mother's responses just inattentive and vacuous, and my father's attentive, and interesting, and constructive.

01-00:36:01

Lage: And problem-solving.

01-00:36:03

Asch: Right.

01-00:36:03

Lage: But did it make you think that the problem lied within you? Lay within you, rather than --

01-00:36:06

Asch: No, not necessarily. Well, I mean, not necessarily, but maybe it lay within me, maybe it didn't, but what could I do to solve it? Which might mean getting somebody to see my point of view, or it might mean trying to do something different myself, but it didn't—I don't think it made me feel like a bad person, it just meant I had some—I didn't want to be helpless. I didn't want to be out of control of the situation. I wanted to do what I could to make things better.

01-00:36:43

Lage: It gave you a way of affecting the world.

01-00:36:46

Asch: Right. So, I mean, I think that was very constructive, about disability or about anything.

01-00:37:02

Lage: Let's talk a little bit about school. You learned to read Braille very early, it sounds like.

01-00:37:10

Asch: No, I learned to read Braille at the same age as anybody learns to read print.

01-00:37:14

Lage: Where did you learn it? How? Was that in school, or?

01-00:37:18

Asch: I was in what was called a resource room for first, second, and third grade, where I had a teacher who knew Braille and taught us Braille, and taught kids how to read and write. And then I was in classes with first, and second, and third graders, for those grades—for science, and social studies, and stuff like that. And then in fourth grade, I stopped being in that resource room, and was just in an ordinary fourth grade class. And no, I didn't learn to read Braille any earlier than a first grader learns to read print. So, it's not accurate, and it's kind of a weird—when you say, "very early," no, it's not very early. It's when—

01-00:38:15

Lage: It's just when it's done.

01-00:38:16

Asch: Right. And I learned to type—my mother taught me to type when I was eight, the summer between third and fourth grade, so that I could type all my assignments, and so I had a typewriter, and I took it to class, and, you know, starting with the first day of fourth grade, I just started writing my assignments, whatever they were.

01-00:38:56

Lage:

Was everything available in Braille? I'm sorry if I ask questions—this is where I say I'm going to ask stupid questions, because I don't know a whole lot about it, but were the textbooks and all the books available to you?

01-00:39:04

Asch:

Yes. The good thing about the New Jersey Commission for the Blind, since they were having blind kids in all these schools, they would work with the towns, and the teachers, and whatever, to get the lists of books that were going to be used, and they would get them put into Braille. Now, there were these sort of glitches. They'd get the social studies book, but instead of starting with the first page, the fourth grade teacher, or the seventh grade teacher would decide to start in the middle, and sometimes I didn't have the volume we needed. You know, we'd have the beginning of the book for the beginning of the school year, but they were going to start with the end of the book and work back for some reason. So, sometimes I didn't have the books, and then my parents would read to me. But usually, I had more of the books than I didn't, and starting in—I don't know—sixth grade or seventh grade, I started reading books on what were called SoundScriber Records. They were these little—this was before tapes, or actually it was just before—yeah, it was before reel-to-reel tapes, and then getting things on tape, as well. So by the time I was in high school, a lot of what I was reading was—if it wasn't in Braille, it was on recording. And I would write my assignments on a typewriter.

01-00:40:43

Lage:

Would you take notes in class on the typewriter?

01-00:40:46

Asch:

No. I would take notes in Braille in class, if I took notes, but I didn't take that many notes. But, yeah, I would take notes in Braille. I would just take notes in Braille, either with a slate and stylus—which was the sort of pencil and paper equivalent. I mean, it wasn't a pencil and paper. I could read it. But it wasn't a noisy machine, it was just a --

01-00:41:24

Lage:

So how did this system work for you? You must have talked to a lot of people over the years that went to state schools for the blind and whatnot.

01-00:41:31

Asch:

Well, most of the people I knew as a kid were in their neighborhood schools, too, because I was living in New Jersey. So I didn't talk to that many people who went to schools for the blind, because we didn't—

01-00:41:45

Lage:

But looking back, did the system work for you, going to the neighborhood schools?

01-00:41:50

Asch: Yes. Oh, I think that was—I mean, in addition to the parents that I had, I think that was the most important decision of—absolutely a formative decision.

01-00:42:08

Lage: Well, talk a little bit more about that.

01-00:42:09

Asch: Well, I think—I mean, it's not that I didn't get teased. I did. I mean, I remember in fourth and fifth grade having kids tease me on the playground. Boys, particularly, would say things like "Blindy! Blindy! Catch me, blindy!" Well, I don't know whether they thought I was going to try to catch them or not, but I did. I usually failed, but I would try. And if some teacher said something stupid, like, "Oh, you can't do this," or, "This will be too hard for you," I would get mad. I was very annoyed with my parents for not fighting the school—the school would not let me take physical education, and I was really mad about that, and that was one of the things my parents wouldn't fight, and the reason they wouldn't fight it was that it wasn't something that was interesting to them. I mean, if they'd cared about it—I don't think it was really so much a matter of overprotection, it was just that they fought about the things that mattered to them, but they were not athletic, and their other two children weren't athletic, and they didn't care about sports, so that was not one of the battles they were going to fight.

01-00:43:30

Lage: What grade was that?

01-00:43:32

Asch: Well, from fourth grade on. That was just—I was not allowed to take physical education. Period. End. And I never did, in grade school or high school. I learned how to climb trees, and I learned how to ice skate, and I did ice skate, and I learned how to swim. I mean, I did physical things, but I didn't play --

01-00:43:55

Lage: Not at school.

01-00:43:56

Asch: I didn't do them at school.

01-00:44:01

Lage: And what was the reason there, given to you?

01-00:44:05

Asch: That it was just going to be too hard. They couldn't think of how I could do all the team sports, and I remember saying, "Well, yeah, I probably can't do the team sports, but there are other things I could do." And they just said, "It's not safe, we're not going to let you do it, end." And when I was a kid, all I could express was that I thought this was stupid. But by the time—and I did complain about it in high school, too, but by then, there were other things to argue about, of various sorts, some having to do with disability, most not,

about just—I mean, my parents and I had other battles, about other things, and so I wasn't going to win that fight, so I just gave up on it.

01-00:45:07

Lage: In general, were your teachers supportive?

01-00:45:11

Asch: Well, some were, some weren't. I think there were certainly teachers who didn't want me in their classes, but they didn't have a choice. I mean, I was going to be in their class. See, I think that one of the good things about being a child in a public school—I think I learned, and I think everybody else learned, whether they liked it or not, I was there. They could hate it, but they didn't get a choice. And I don't think it ever—I don't think I ever viewed it as—there was a summer advanced composition course that was offered during high school, and I wanted to take it, and I went to the guidance counselor, and he said the most stupid thing, it was like, "Do you think you should inflict yourself on a stranger?" And I sort of said, "What are you talking about?" And I went home, and said what an outrageous thing that was, and my mother called up, and I took the course. But the point was nobody was going to say that sort of stuff and get away with it.

01-00:46:39

Lage: And that sounds like something that came from within you, not something that your parents had to tell you.

01-00:46:48

Asch: No. No. I mean, when I was ten, the Jewish Braille Institute, which is an organization that put books and stuff in Braille for Jewish people—you know, prayer books, and Hebrew language books, and Jewish history books, and all this stuff. They wanted to raise money, and they had some Passover TV show, and they got five of us, or six of us, or four of us, or something, to come and be poster children. And I remember coming home from the first day of this filming, or whatever it was, really mad, and saying, "This is just the most..." I mean, I don't remember exactly what the words were, but, "This is this maudlin, pathetic thing. I don't like it." And I sort of remember some kind of narration about, "When the children were wandering in the desert, they were blind people, and they were tragic people, and they were this, and they were that." And I went home, and I said, "Uh-uh. I don't want—we have to do something about this. I don't like this. I don't want to be involved in this." And I think we got the script changed. I mean, I'm sure we didn't get it changed as much as it should have been, but --

01-00:48:26

Lage: But your parents respected your attitude.

01-00:48:29

Asch: Yeah. I mean, I think they did. I think they shared it. You know, who knows? I found a letter that my father wrote to the rabbi who bat mitzvahed me, thanking him—this was his first week at the congregation, and he was young,

and hadn't done a bat mitzvah before, and I found it—I don't know—fifteen, twenty years ago, thanking him for being a good rabbi, and saying something about it might have been more of a challenge to work with me than to work with another kid. And I remember, actually, at the time I read the letter, being a little surprised. Because I think—it's hard to know how much my father viewed being the father of a blind child as more challenging. I think he did in some ways, because he said he had to think more about how to solve a particular kind of problem, but I think he found it interesting. I think that was the thing that was so good about him, about his being—and I think Susan and Carl would say that about the way he was with them. I mean, they weren't blind, but they had their own issues, and I think they felt he was very good at thinking about how they should live their lives. And we were all very different from one another in some ways, and not so different in others.

But I think that he and my mother, the gifts that I think they had as parents—and this is actually related to a lot of other work that I've done—I think the gifts they gave us as parents were letting us be who we were. I mean, it's not that they didn't want things for us, or of us, or from us. They did. But they learned that we were going to be very different people, and we were going to be who we were, and some of it, they were going to like, and some of it, they weren't. I mean, you talk back to our mother—Carl says that the one time my father ever hit him was when Carl was disrespectful to our mother, and I remember a similar kind of thing. My father took me for a ride when I was finishing college, and said, "You're treating Mommy in a totally unacceptable way, and you're going to stop." And he was right.

01-00:51:52

Lage:

What kind of expectations did they have for your future? Was anything voiced?

01-00:51:56

Asch:

I don't think they knew. No.

01-00:52:00

Lage:

By teachers, or parents?

01-00:52:01

Asch:

Well, I was going to go to college, but I knew that just because this was sort of Jews and education. You went to college.

01-00:52:11

Lage:

Even though your parents hadn't?

01-00:52:13

Asch:

Well, but they aspired. I mean, they were self-educated people, and they would have liked to go to college, and if circumstances had been different, they would have gone to college.

01-00:52:29

Lage: So, that was always in the plan. Aside from the fact, I'm going to guess you were a good student.

01-00:52:36

Asch: Yeah, I was a good student, and I liked being a good student. I mean, I remember coming home with my first report card from first grade, getting a "weak" in posture, and being very upset. And my father kind of saying, "You know, Adrienne, it's all right. You can improve, but we're not going to stop loving you." I think they always felt that I had very high expectations for myself, but they, I think, tried not to give me the feeling that I wasn't a good person if I didn't meet those expectations.

01-00:53:32

Lage: Well, did you get any messages that life was going to be different for you because you were blind?

01-00:52:37

Asch: No.

01-00:52:37

Lage: As you became an adult?

01-00:52:40

Asch: Not from anybody until it was.

01-00:52:43

Lage: [laughter] We'll talk about that later.

01-00:52:44

Asch: No, I mean, I didn't. I was going to go to school, I was going to go to college. I had a boyfriend, I expected to have a boyfriend. I was going to have kids. I mean, I was going to have a job, I was going to do what everybody else did. I've never been a big person on role models. I know role models are really in, but when I was a kid, every now and then the New Jersey Commission for the Blind would say, "All these blind teenagers should meet some blind adults," and I found the whole thing stupid. I wasn't worried about being a blind adult. I knew lots of adults, and I figured I'd be an adult when I got there.

01-00:54:48

Lage: You didn't feel the need for a blind role model?

01-00:54:51

Asch: No, I really didn't. Most of the people that I met who were sort of shown up to me as role models, I actually didn't like. I mean, I knew some blind grownups, and if I liked them, I liked them, and if I didn't, I didn't. Actually, this was interesting. When I was sixteen, I went to stay for the weekend at the home of a music counselor from camp, who was blind, and his wife, who I'd been friends with, and I was horrified. I mean, I liked them a lot, but I was just horrified at the way Stan treated Nancy as a kind of servant, and at the way

she was submissive, and I just thought, "He's being the stupid dependent blind person, and she's doing this stupid sort of womanly, submissive waiting on him." And I just thought, "This is not a way for anybody to behave, male or female." It was sort of—I was not going to be that kind of woman, and I was not going to be that kind of blind person.

01-00:56:03

Lage: You've had a negative role model.

01-00:56:06

Asch: Right, but it wasn't—I mean, I was actually very surprised, because I really liked them, and when I was out their house, and just saw the way they interacted as a couple—and I hadn't spent that many times with couples, paying attention to how—as a kid, you don't necessarily notice how couples are. I mean, I spent time with my aunt and uncle as a couple, and I liked their way of being better. Ultimately, they didn't stay married, but I didn't like that version, and I knew that I wasn't going to be that kind of woman or that kind of blind person.

And at camp, where I made a lot of friends—I mean, I had blind friends. I always had blind friends, and I didn't think either that I should have them or that I shouldn't. When I was twelve, actually, a girl who was a little older than I was was going out with a boy who was blind, and I remember hearing people saying, "Oh, they shouldn't go out. Blind people shouldn't marry." And I remember saying, "Well, wait a minute. There's something wrong here. If it's okay to be blind, then it's okay to have blind friends and blind boyfriends. This doesn't make any sense. You can't say it's okay to be blind, and then say, 'You shouldn't like each other.'"

01-00:57:39

Lage: So, they were saying two blind people shouldn't pair up?

01-00:57:45

Asch: Well, they were saying they shouldn't get married. I mean, these kids were fourteen. They weren't going to get married. But that wasn't the point. The point was that I don't think I accepted—to the extent that I heard negative messages, I don't think I internalized very many of them; I just thought they were wrong, and said so.

01-00:58:16

Lage: You didn't internalize them, but you heard them.

01-00:58:18

Asch: Yeah, but I didn't hear that many of them. I mean, those were much more exceptions to either, "You're a kid, and you're blind, and that's not a big deal." My parents never said things like that, but if I heard them from teachers or books—I mean, I remember reading some really stupid book about a blind boy, or grownup, or whatever, and complaining to my mother about, and just saying it was a really stupid book about this helpless kind of person, and I

didn't like the way he was portrayed, but I didn't—I read them, and I was interested in them, but I didn't take them in, in a bad way. They were wrong, and that was that.

01-00:59:33

Lage: Well, after all, you were taught to think critically, it sounds like, so you were applying that lesson.

01-00:59:40

Asch: Yeah, but it wasn't very hard. I mean, when I was in eighth grade, there was a debate that we had to do, and I volunteered for the side of—and this was just crazy—that the world would have been better off if Hitler had won the war. Now, why did I do that? I don't know. It's not that I believed it. I knew I didn't believe it. And my parents were sort of horrified that it was a debate topic, but they thought it was fine. They didn't want me to believe it, but they knew I didn't, and if I wanted to do it as an intellectual exercise. . . . They laughed about it.

01-01:00:26

Lage: I'm going to have to stop this here, because we're running out of tape. So let's—I hope you're not in the middle of a thought—

01-01:00:33

Asch: No.

End Audio File 1 asch_adrienne1_06-19-07.mp3

Begin Audio File 2 asch_adrienne2_06-19-07.mp3

02-00:00:03

Lage: Okay, we're on tape two in the interview with Adrienne Asch, and again, it's still June 19, 2007. Now, Adrienne, as soon as we turned it off a minute ago, you mentioned something about the hard parts. Where were the hard parts in those years?

02-00:00:29

Asch: Well, the hardest parts that I had were in fourth, and fifth, and sixth grade, where I didn't have as many friends as I wanted, and I got teased. And then in sixth grade, I tended not to get teased, but it seemed to me that I was being ignored, and I remember saying that being teased was bad, but being ignored was worse, and I really didn't like that.

02-00:00:52

Lage: And what made you connect it with being blind, or did you connect it with being blind?

02-00:00:56

Asch:

Well, I didn't. In fact, that was one of the things that—it seemed to me that I had friends at camp, and I didn't have friends at home, and it's true that the kids at camp were blind and the kids at home weren't, but I remember very clearly posing the question to myself, "Was it a matter of blindness, or was it that I was different at camp than I was at home?" And I think that was a good way to pose the question. I don't think I ever entirely figured out the answer.

But starting in seventh grade, I started making more friends, and had a different teacher, who I think was much better at building community in her own classroom than some other teachers had been. I think that was good. That pretty much continued, so seventh and eighth grade, I had more friends. Then in high school, that really continued, and one of the things that I was very clear about—I was a reader. I was a very avid reader, and I really liked that. I certainly liked being a good student, but it was very clear to me that I read books to some extent because I didn't have friends, and when I had friends, I was going to read fewer books. And to some extent, that was true, and it's still true. Even though I'm still a reader, and an intellectual in certain kinds of ways, and an academic, and things like that, I'm a very social person. I've always been a social person. I like having friends, and I liked having friends then, and that was true when I was twelve, and it's true now. I mean, it was true when I was five.

When I was in high school, I got very involved in the high school chorus, and that was a big center of social life. The chorus was—well, we did a lot together. We had a folk song group, and a group of us created a summer choir and orchestra that we ran ourselves. Several of my close friends were involved in that, and then I started going out with somebody who was involved in that. He was three years ahead of me. He was a freshman in college when I was a sophomore in high school, but we were a couple for many years—well, for the next five years. That was a complicated thing, because he wasn't Jewish, and he was not very political, and those were things my parents didn't like. Well, I didn't care about the Jewish part, but I did care that he wasn't very political, and he didn't pay attention to the news.

02-00:04:51

Lage:

And so much was happening in those years.

02-00:04:53

Asch:

Right. So, we sort of fought about that, but he was a very good person, and very good for me in lots of ways. But my parents and I started having battles about how much time I was spending with him versus how much time I was spending with the family, and how much time I was spending with my friends. You know, there was the sort of subtext that you have as a teenager about are you going to lose your virginity, and you know, that kind of stuff. And then there was the issue of was I going to—he was involved in church music. He was an organist and a choir director. And, you know, this was where the sort of prejudiced parts of my parents' Jewishness came in. I mean, Jews were

classical musicians, but they weren't choral musicians. They were violinists, and pianists, and—but they weren't singers, in my parents' experience. So the idea that I was singing all this Christian music—you know, Bach, and Mozart, and requiems, and masses, and motets and things. They didn't like it. I mean, they didn't think it was wrong, they just wished I were passionate about something else.

02-00:06:25

Lage:

But it was all Christian music, basically.

02-00:06:27

Asch:

Right. So, we had a lot of fights about that, and so a subtext of my high school life was fights about Win, my boyfriend, and fights about how much music I was doing, and where was my social conscience, and—I mean, I had one, but I was really passionate about all this music stuff. In my father's view, what he wanted me to do was marry a Jewish intellectual and go into the Peace Corps. Which was pretty good, you know? That's a pretty good thing to want your daughter to do. I wanted to marry a Jewish intellectual musician, and I didn't care about the Peace Corps, particularly. But I had a very good time in high school, actually, and then I did—except for fighting with my parents about things like that, I had friends.

Actually, *Inherit the Wind* was a big part of—my junior year, we put on *Inherit the Wind*, and this was a big kind of controversial act in our high school—not controversial, but we really came from this very crummy, mediocre kind of all-American high school that liked cheerleaders and football players, and kind of stupid musicals. So putting on *Inherit the Wind* was kind of—I don't know. It was dramatic.

02-00:08:27

Lage:

Although I don't remember that as a time when evolution was being questioned as it is today.

02-00:08:32

Asch:

No, no, no. It wasn't. It wasn't being questioned, but just the idea that it was a serious play. I remember my sophomore year and junior year, we had history taught by these really right-wing DAR-type [Daughters of the American Revolution] teachers, and I got really mad at how stupid the high school textbooks were, and came in and said, "You're not talking about the Pullman Strike of 1893, or Clarence Darrow, or this or that." I persuaded them—I don't know how—to let me teach a session of a history class, because I felt that the history books weren't telling them things that I was reading in just books I was reading. Why they let me do this, I don't know, but they did.

02-00:09:21

Lage:

So what did you teach a section on?

02-00:09:23

Asch: Oh, I don't know. I just did something on Clarence Darrow, or... I don't remember what I did.

02-00:09:37

Lage: Were you in *Inherit the Wind*?

02-00:09:39

Asch: No, I wasn't in it. One of my best friends had the Clarence Darrow part. But I think I was part of the publicity, or whatever. It was very exciting.

02-00:10:09

Lage: Is there any more to say about the hard parts up to that point?

02-00:10:19

Asch: I mean, as I say, in high school, the hard parts were fighting with my parents about religion, and choral music, and how much time I was going to spend with Win versus how much time I was going to do things with the family, and stuff like that.

02-00:10:43

Lage: Typical teenage stuff?

02-00:10:45

Asch: Right. And they were—some of those battles were really big. In my junior year—junior year? junior year—the all-state chorus didn't want me and some other blind kid who'd gotten into the all-state chorus to go on one of their field trips. My parents and I were not getting along very well, but my parents knew that if the all-state chorus didn't let me go on that field trip, life was going to be utter hell. So they—and, I guess, the other family—signed some insurance waiver that they wouldn't—I don't know, they wouldn't sue the bus company if I got hurt, or something really dumb. It was really stupid. And my father—this was great. At 4:00 in the morning, we all were getting on the bus to go off on this three-day field trip, and as I boarded the bus, my father said, "Adrienne, do you think you could go through a plate glass window or something?" And people thought, "What is he talking about?" But it was sort of like, "We had to sign this form? Make it good."

02-00:12:24

Lage: [laughter] That's great.

02-00:12:29

Asch: And so even though we were not getting along, they certainly didn't want me not to do what I wanted to do, and they also knew that I would never—they were never going to hear the end of this. But, I mean, it would have been a really crushing thing. I was so excited about being in all-state chorus, and it was such a big deal, and --

02-00:12:50

Lage: But you must have had to audition for it?

02-00:12:52

Asch: Yeah, well, that wasn't the problem. They would let you be in the chorus, they just didn't want you to go on the field trip.

02-00:12:58

Lage: I see. So you were in the chorus, and did other chorus things.

02-00:13:02

Asch: Right. But it was just this one field trip. But anyway, we went on it—I and this other blind kid both went on it, and we went on it the following year, and...

02-00:13:17

Lage: Okay, now we're back on, recording, after a brief break—more than a brief break. A lunch break. I wanted to ask you about camp. You mentioned camp more or less in passing, but tell me about what the camp was, and how that might have been important in your life.

02-00:13:42

Asch: Well, it was a camp for blind kids run by the New Jersey Commission for the Blind, and it was a camp, more or less.

02-00:13:54

Lage: Was it every summer? Did you go every year?

02-00:13:56

Asch: I went starting when I was six, and I went pretty much every summer until the end of my—I went until I was 16. I didn't go the whole summer. Sometimes I went for eight weeks, sometimes I went for six weeks, sometimes I went for four weeks. It depended on what else was going on. I liked it. I made friends. I had a good time. Some of those friends stayed important for a really long time in my life, and particularly when I wasn't making friends at school. I mean, I think it was a very good experience in the sense that we kind of compared notes about how our parents were treating us, and how teachers treated us. There was a lot of informal kind of sharing of what did it mean to be a blind kid in the public schools. There were regular activities of hikes and camping, and swimming, and rowing, and stuff like that. I mean, so it had a lot of crafts and things you would do at any other camp. I'm not sure. It was a good experience, I'm really glad I did it. I didn't like the fact that—well, it wasn't clear, for one thing, if we were in the neighborhood schools, why weren't we going to the neighborhood camps?

02-00:16:32

Lage: You thought of that at the time?

02-00:16:33

Asch: Yeah. And I didn't like that. But I did like my friends, so I was perfectly happy to see my friends. It was free, and my parents didn't have a lot of money, so I don't know if they could have afforded a camp that you had to pay for. I mean, maybe they could have, but it was free. There were kids I saw

during the year. There were two or three friends that I wanted to see during the year, and our parents would get us together, which was a little bit inconvenient, because there wasn't a very good bus system in New Jersey, so they would have to drive a couple of hours each way for weekends, but we did that. Not a lot, but some—enough.

02-00:17:39

Lage:

Did you feel any more closely bound with those friends than the friends from school?

02-00:17:45

Asch:

In fourth, and fifth, and sixth grade, yes, because I didn't have very many friends in school. Starting in seventh grade, I didn't feel any less bound to my friends at camp, but I didn't feel more bound. It wasn't as though they were like my best friends and the school friends were not best friends. There were two kids I was quite close to in high school who lived in Princeton. Princeton is an hour and a half from the town that I lived in, in Ramsey, and I was quite good friends with them, and I stayed good friends with them—well, one I'm still friendly with, and the other one died, but we stayed friends.

02-00:18:44

Lage:

Some people talk about camps like Camp—is it Jened? Camp Jened in New York—as being sort of a place where the first sense of a disability identity took place.

02-00:18:57

Asch:

I knew that's what you were getting at, but—I liked the camp, and I liked my friends, and as I say, when people said stupid things, like sometimes, you would hear counselors say, "Oh, this family has four blind children. How could the parents have four blind children. Isn't that disgraceful? Why didn't they stop at the first one?" And I found that offensive. I mean, it was like, if it was okay to be blind, then it was okay to be blind, and they shouldn't have to stop at one, or two, or four. But again, if you want to call it a disability "identity," I don't know that I needed camp. I was perfectly happy to have my friends at camp, and you know, I would write letters to them during the year, and I looked forward to writing them, and I looked forward to getting letters, and I talked to them during the year, but the ones that were my friends. I didn't feel as though camp was my community, and home was some horrible thing.

02-00:20:20

Lage:

It doesn't sound like it was a political experience, either.

02-00:20:22

Asch:

Well, it was a political experience in that attitudes that I've had as an adult, I certainly clearly had as a child. I mean, that is, when people said, "Blind people shouldn't date each other," I thought that was wrong. I didn't think they should be required to date each other, but I didn't think they shouldn't date each other.

02-00:20:45
Lage: But you do remember the remark by the counselor --

02-00:20:47
Asch: Yeah.

02-00:20:48
Lage: -- about the four children --

02-00:20:48
Asch: Yeah. I do. And I didn't like it. And there was a certain kind of hierarchy to some extent. Kids with partial sight were viewed as better by the counselors than kids who were totally blind, and I found that stupid and offensive. But I didn't fight it. I just ignored it. Well, to some—If I heard things I didn't like, I said I didn't like them.

02-00:21:29
Lage: Were the counselors, any of them, blind, or the people who ran the camp?

02-00:21:34
Asch: Some of them were. Yeah, but that was another thing that was very—the cabin counselors, the counselors that were sort of in the cabins usually weren't. Activity counselors might be blind—athletics, or music, or something. But usually the cabin counselors weren't blind, and I thought that was wrong. So at times, I thought there were these sort of funny implications I didn't like, but I didn't take them very seriously as communicating messages. I mean, even if they were communicating messages, I didn't believe them, so I didn't care about them. I was going to do what I wanted to do, and that was that. I didn't --

02-00:22:46
Lage: You weren't listening to the rest of the world, it sounds like, if you didn't like the message.

02-00:22:52
Asch: No, I guess I was—but it wasn't the world that mattered to me, because it was nobody—the only people that could hurt me were people I cared about, and I knew that very early, actually. When I was thirteen, we had to read the poem, "If," in grade school. I don't know if you remember that poem, but it was interesting. It has --

02-00:23:20
Lage: "If you could be a man, my son."

02-00:23:22
Asch: Well, right, but—"If you can keep your head when all about you are losing theirs and blaming it on you," or whatever. And I remember the line, and I remembered the line at the time, that said, "If neither foe nor loving friend can hurt you," and I remember saying to somebody—to myself for sure, but maybe to some other person, out loud—"My foes can't hurt me, but my

friends can." So if I had had messages from parents or teachers or friends that said, "You're not good enough," or, "You're second class," or, "You can do this, but you can't do that," or whatever, that would have hurt me. But I didn't. So if people I thought were stupid said things that I thought were stupid, I just didn't care. I just thought they were stupid.

02-00:24:22

Lage: I can understand that.

02-00:24:28

Asch: And by the time anybody—to some extent, by the time anybody important to me, or important in the power of my life, was saying things that I thought were wrong, I had—I mean, I don't know if you read the piece, "Personal Reflections,"¹ but it's actually—

02-00:24:47

Lage: I did.

02-00:24:48

Asch: I'm sorry?

02-00:24:49

Lage: I did. Yes.

02-00:24:50

Asch: I think that is one of the most personal pieces I've ever written, and a very important piece, in a way, because I think it positions how I felt in 1984 when I wrote it, and in many ways, how I feel now. I think I have a disability identity, but I'm not—you can force me to have it, but I'm not interested in it.

02-00:25:23

Lage: That's quite interesting. You more or less said you had to develop it because of the outside world insisting on it, almost.

02-00:25:34

Asch: Right. But I feel the same way about being female and being Jewish. I don't like identity politics.

02-00:25:48

Lage: We must talk about that much more, I think. I think it's important. But I have this chronological agenda—

02-00:22:58

Asch: Well, actually, wait. Let me just go back to something.

02-00:26:00

Lage: Yes, please.

¹ Adrienne Asch, "Personal Reflections," *American Psychologist*, May 1984, vol. 39, No. 5, 551-552.

02-00:26:02

Asch:

When I was eleven, or twelve, actually—there was this stupid—in seventh and eighth grade you had these dances. You had these private dancing lessons in the grade schools, like Friday nights. They were hideous. I hated them. I hated them—boys didn't want to dance with me, and I didn't like that, but I also just didn't like dancing, and I didn't like the music, and I was trying to like it because you were twelve and you were supposed to like it, but the truth was I really didn't like it. Anyway, but there was one day when Linda Eckhouse—a friend of mine, aged twelve—went to this dance, and I think didn't have the right amount of change, or something. So she couldn't get in. A few days later, my mother, and her mother, and some other mothers were having this phone conversation about how Edna Lewits—who was Jewish, and Linda Eckhouse was Jewish. Edna Lewits, who was Jewish, didn't help Linda solve her problem, and why didn't the Jews stick together, because it was embarrassing to have Linda not be allowed to get into this dance, and the Jews should take care of their own. Well, I remember hearing this conversation and thinking, "Oh, God. This is so stupid. I really can't stand this." And then I sort of thought, "I wish we all lived in Israel, so that everybody would be Jewish, and we wouldn't have to all stick together and act as though the Jews were against the gentiles." So I remember have this sort of flash of, "I don't want to like people because they're Jewish, or stick together with them because they're Jewish." I just thought this was all stupid.

This may seem like a digression, but it's not, because it's very related. The worst parts of kind of paranoia of, "The gentiles are going to get you, and there's anti-Semitism under every bush," that I didn't like had a lot to do with how I in some ways felt then and feel now about disability. I remember when I was little and my parents were talking about anti-Semitism, and I remember saying, "Well, you know, I don't experience anti-Semitism, because if people want to tease me, they can tease me about something much easier, and they will." But I think a lot of the attitudes that I have about all of this identity stuff were formed in reaction—both good and bad—to how I was raised. And I think my parents did a lot that was right, but I think some of their own kind of post-Holocaust paranoia about Judaism and about anti-Semitism—I don't like boxes. I don't like categories. I don't want to be told what category I'm in, ever.

02-00:29:39

Lage:

And it seems that that's the way the disability studies—well, many studies—have gone --

02-00:29:47

Asch:

Yeah, but I don't like them.

02-00:29:49

Lage:

Well, that's—[laughter]

02-00:29:55

Asch: I mean, I do them, but I don't like them.

02-00:29:56

Lage: Are you an active voice against that trend?

02-00:30:01

Asch: You'd have to ask somebody else. I mean, I do what I do. In that sense, in a way, maybe I live out that other thing about my father. He lived the way he believed, for good or bad. I taught at a women's college—Wellesley—and I was never all that excited about its being a women's college. When Geraldine Ferraro ran as a vice presidential candidate in 1984 I didn't like her, and I might have been happy that a woman was running, but I didn't like her, so I wasn't excited that she was running. And it was sort of like, "Yeah, I'd be happy to have a woman as vice president, but I want a woman I like." And so the fact that Hillary's a woman isn't going to get me excited if I don't like her. I don't think I like her any less because she's a woman. I don't think because she's a woman, she's supposed to meet higher standards. I just don't like her.

02-00:31:13

Lage: Whether she's a man or a woman --

02-00:31:16

Asch: Right. So --

02-00:31:21

Lage: Well, I think we'll be coming back to this as we move you through.

02-00:31:24

Asch: Yeah, but I guess I just think those attitudes were formed --

02-00:31:28

Lage: Early.

02-00:31:28

Asch: -- or shreds of those attitudes were formed very early, so you couldn't say things negative about blind people as a category without hearing it from me. I wouldn't stand for it. But at the same time, I wasn't interested in—I wasn't interested in it as an identity.

02-00:31:53

Lage: And you never were. Is that --

02-00:31:56

Asch: No. That doesn't mean I haven't done a lot of work around it, but I'm not interested in it. Carol Gill once described me as having an identity about disability that was positive but not central. And I don't even necessarily like the word positive. I mean, I don't care about it. I mean, I'm perfectly—I'm blind, and I'm perfectly willing to be blind, and if I'm not blind . . . I don't know. I don't have to be blind. I just am.

02-00:32:39

Lage: Yeah. And that's one aspect.

02-00:32:40

Asch: Right. I mean, I don't have to be Jewish, and I don't have to be female, but I am Jewish, and I am female, so that's it.

02-00:32:48

Lage: Now, Carol Gill seems to embrace a disability identity more.

02-00:32:51

Asch: Well, lots of people do. But I don't. But I don't think I reject it, either. That's the other thing. I'm not interested in rejecting it, and I think actually that's another relevant—when Jews in New Jersey would have Christmas trees, or would change their names, or would do things to pretend they weren't Jewish, or try to pass, my parents had real contempt for that and scorn for that, and dislike of it, and I agreed with that. I mean, I didn't like it either. It's like, "You are Jewish. Don't pretend you're not." So I think that that's the same sort of thing that I feel about blindness, or being a woman. Is this different from what I've said in my published work that you've read, or not?

02-00:34:13

Lage: I was just trying to think how it fits with—to skip way ahead—the prenatal testing issue, in the sense that testing and rejecting a child or a potential child who might be disabled in some way some people feel is an offense against living disabled people.

02-00:34:44

Asch: Well, I think it is, but I also think it's an offense against good parenting.

02-00:34:52

Lage: You have a broader look at it, in many ways.

02-00:34:58

Asch: Well, I think so. Maybe.

02-00:35:04

Lage: An offense against good parenting in what respect?

02-00:35:08

Asch: Because you should deal with who your child is, and that's what you have to do as a parent anyway. And you can try to teach your child to use a fork and a spoon, and say "please" and "thank you," but your child's going to develop interests and tastes, and some of them you'll like, and some of them you won't, and that's what you have to deal with as a parent, and so not accepting a characteristic of your child that your child can't change—like having a disability—I think is not a good way to treat any child.

02-00:35:53

Lage: I still think we should leave this and come back to it, but I like that you're tying it in to these very early attitudes that you have, that seem very central to

your being, and to the way you were raised, really, one way or another. Some in reaction to, and some embracing.

02-00:36:19

Asch: Yeah. And I think more embracing than in reaction to.

02-00:36:24

Lage: Except you used the example of the Jewish...

02-00:36:27

Asch: Yeah, well, that's that part. But see, I embrace the, "Don't change your name, and don't assimilate, or don't pretend you're not Jewish, because you are." That I thought was fine. What I didn't like was the kind of—we all had to protect each other because we were Jewish, or like each other, or stick together. I thought that was stupid.

02-00:36:57

Lage: Okay. We'll come back to this, but let's get you into college. Unless there's more you want to say about the pre-college?

02-00:37:11

Asch: Well, I guess there's a little bit more I'd like to say about pre-college. From what I'm told, I had a very unusual high school experience as a kid with a disability, because I had a really good time in high school. I really had friends, I did well academically. It wasn't a very good high school, and I knew that, and that is going to be very relevant later, when I get to college. But I didn't experience any discrimination, really, that I couldn't solve.

I mean, that wasn't absolutely true. I mean, I was teased, and I had these teachers who didn't always want me in their classes, but they didn't have any choice, and they did have me in their classes, and they usually got over it. I forget—there was some history prize that they wouldn't let me take a test for, because they wouldn't either give it to me in Braille, or read it to me, or something. They didn't want a blind child winning the history prize, and I was really mad about that. But mostly—well, actually, this is relevant. In 1963—I used to get this magazine called *The Jewish Braille Review*, which was a Braille magazine put out by that thing called the Jewish Braille Institute. And it was mostly a grownup magazine, so most of the stories in it were just too grownup for me. But I would read some of them. There were two things that were—three things. One, there was a paragraph that I can still remember to this day about a woman named Penina Moise, who was described as "The greatest blind woman Jewish poet of the Confederacy."

02-00:39:31

Lage: [laughter] How many were there?

02-00:39:32

Asch: Well, I remember reading that, and I kept thinking, "I want to know who her competition was for that honor." I just thought it was the silliest, funniest—it

was just a riot. I just loved it. I loved it for its just absurdity. And I also read about Jacobus tenBroek, and this National Federation of the Blind, and I read about it quite approvingly, because the Jewish Braille Institute—the head of it liked Jacobus tenBroek, but I remember reading these articles—they would reprint speeches of his, and I remember reading a speech of his about blind kids not being allowed to run for student council president in their high school, or blind people not being allowed to get safety deposit boxes, and I just thought, "This is crazy! This isn't true. I never heard of this." And there was also an article by Peter Putnam, who was a historian—I think a failed historian, but anyway. He might have had a PhD in history, and he was blind, and he wrote this article called—I don't know, something like, "Blind or Black," and it was all about whether it was easier to be blind or black in this country, and I remember being horrified, because it was sort of like, "Blindness is a real handicap, but blackness is discrimination," and I remember thinking, "Of course it's harder to be black in this country. This is ridiculous. What are you talking about? I'm not lynched. Nobody's stopping me from doing anything I want to do." But --

02-00:41:26

Lage: But tenBroek's article showed you that people were being stopped --

02-00:41:29

Asch: Yeah, but I just didn't believe. I just did not believe it. I was shocked. I was totally astounded.

02-00:41:36

Lage: And this was high school?

02-00:41:37

Asch: This was high school. And so to me, it was very clear that being blind was not a problem, and being black was a big problem. All of my political consciousness was all about civil rights, and as far as I was concerned, that was racial civil rights, and I was really interested in that, and that's why I wanted to go on the march in 1963. But I had no—in sixth grade, I felt that blindness was discriminated against, because I really felt mistreated, and blindness was a piece of the story of that. But by—

02-00:42:24

Lage: But mistreated socially?

02-00:42:26

Asch: Yes. But by high school, I really didn't feel mistreated socially. Or at least, I had my friends, and if other people didn't like me, I didn't like them either, actually, because I thought all the cheerleaders and football heroes were just people I didn't like, and I didn't want to be popular, because I didn't like the popular kids. That was a very important recognition, that by the end of my freshman year in high school, I realized that even if I wasn't popular—the way that term was defined—I didn't like them. I didn't need to be popular with them, because I just didn't like them. And once I had my set of friends that I

could debate politics with, or listen to music with, or do other things with, and I had this boyfriend—so I felt as though I had my niche, and it wasn't everybody's niche, but it was the niche I wanted.

02-00:43:35

Lage: Right. And you didn't see the civil rights nature of the disability issues yet. Or

--

02-00:43:42

Asch: No. I mean, that is—well, when I was in high school and I was applying to college, I got into two of the colleges that I wanted to go—well, one of the colleges that I wanted to go—Swarthmore—and I didn't get into Radcliffe, but I didn't want to go there. And my high school best friend from two years ahead of me, who was way smarter than I was, didn't get into Radcliffe either, so I didn't feel all that upset, and I really didn't want to go to Radcliffe. I got into Douglass, which was the state school in New Jersey that pretty much had to take you if you were in the top half of your class, and I was, so. And then I had this interview, which I also knew was unusual. They insisted that I come meet them.

02-00:44:34

Lage: Is this Douglass?

02-00:44:35

Asch: Yeah. And I knew that this was atypical. So I went down, and they said, "Well, we have to accept you, but we don't want you to come, because we're afraid you will get hurt crossing Jackson Street." And I said, "Well, I'm going to work in New York this summer, so I'm going to cross a lot of streets, and I'm not worried about crossing Jackson Street, but I don't want to go here anyway, so if get into Swarthmore, I'm not going to go." But I was totally pissed off and disgusted, but I didn't want to go there—and besides, they were going to have to take me anyway. So they could say stupid things like they were worried about my crossing Jackson Street, but I wasn't worried about crossing Jackson Street. So it's not that I didn't—it's not that I hadn't had anything bad happen in terms of blindness, or stupid, or even mean --

02-00:45:27

Lage: And even discriminatory.

02-00:45:28

Asch: And even discriminatory, and I knew it, but it hadn't stopped me. A couple of years before that—I mean, I had some sense that blindness might stop me in the sense that people could treat me badly, might say stupid things, could be wounding. My boyfriend Win's friends teased him about going out with a blind girl.

02-00:46:15

Lage: Where did Win go to college?

02-00:46:17

Asch:

He went to this music school, called Westminster Choir College. I appreciate that he didn't let them—I mean, I didn't like when they teased him, and I didn't like when they teased me, but it didn't stop him from being involved with me, and I don't know. I didn't know what lay ahead of me, which actually still didn't really happen in college, either, but I didn't know that blindness was going to be a political issue. I knew that people could say and do stupid things. I also felt that I'd been able to solve most blindness-related problems, so that when I was in all-state chorus, I remembered meeting kids and getting to know them, because it was so exciting to talk about what you were singing in your own high school chorus, that you could make friends. I mean, I remember making friends because there were so many avenues of ways to have friends. There were so many commonalities that it felt as though I could get over people's initial awkwardness, or resistance, or fear. So I wasn't worried.

I mean, I didn't think blindness was going to be a problem in college, or in making friends, or in having other boyfriends, or in having a career. The things I wanted to do, when I wrote on my college application essay, I wanted to do counseling, or civil rights work, or high school humanities teaching, or journalism—I never thought I was going to have any problem doing any of those things. And so later—I mean, in the last forty years, as blind people or other disabled people have said to me, "Well, what should I expect of myself as a disabled person or as a blind person, and I want to know other blind role models," I've often said, "You don't need a blind role model. You need a role model. You need somebody you admire, that you respect, who believes in you. They don't have to be blind. They don't have to be a woman. They don't have to be anything, except that you have to admire them, and they have to believe in you. And don't ask yourself, 'What do other blind people do?' Ask yourself what you want to do. And that's the only important question. If you want to do something, you'll do it."

02-00:49:55

Lage:

As a teacher working with students, would you give that same advice to a black young person? Or an Asian young person?

02-00:50:05

Asch:

Yes. I would. I mean, I wouldn't say, "Don't talk to someone who's black or Asian." But I would still say, "The thing that you have to figure out is who you want to be, and you have to find people that believe in you, and you can't just assume that the only people who are going to believe in you are black or Asian."

02-00:50:41

Lage:

Let's talk about college. It would be great if we could get you to New York today. I bet we don't, though.

02-00:50:49

Asch: Oh, no, actually, at 4:00, I have to stop.

02-00:50:53

Lage: Oh, that's right. And it's ten to 4:00. I hadn't realized.

02-00:50:58

Asch: Well, all right. I know that we're not going as fast as you want. I'm going to give you one more high school anecdote, and then we can get to college. In New Jersey, you could get your driver's license at seventeen. That meant that Carl, my brother, was seven when all my friends were getting their drivers' licenses. And Carl said to my father, "Daddy, why isn't Adrienne getting her driver's license?" And my father said, "Well, I really don't think that the police would like it if Adrienne drove a car." And Carl thought about this for a few minutes, and said, "Why? I'll sit next to her and tell her when to turn."

02-00:51:40

Lage: [laughter] Oh, that's beautiful.

02-00:51:44

Asch: And I really like that story. And my father liked that story. I think that had a lot to do with—Carl and Susan saw me as their big sister, who brought a lot of friends into the house, some of whom they liked, and some of whom they didn't, and they would tease me about my boyfriend, or they would get mad at me for babysitting if they would try to get away with things and I wouldn't let them, or whatever. But you know, I think I had a pretty—not idyllic life. I was unhappy about things from time to time. Very unhappy, and I was not silent about what I was unhappy about, but it's not that I didn't think blindness could be a problem or would be a problem, ever, but I—

Well, here's an interesting thing that gets me into college. I asked for a single room. Most people had roommates their freshman year, and I asked for a single room, and I asked for a single room for a couple of reasons. I mean, I had a Braille writer, and a typewriter, and a tape recorder, and lots of bulky equipment that was going to take up a lot of space in a room that I was going to have to bring with me. And I also didn't want someone to feel that they were stuck in a situation that they didn't like with a roommate they were afraid of, having to get along with me and my equipment, if they didn't want to be. And I had a sense that it would be much better for me and any future friends I made not to start out that way. And so it's not to say that I didn't have some sense that people couldn't like—it's not that I didn't think that blindness could be a problem, but I thought I could solve it. I thought a way to solve it was not to require somebody to be my roommate, especially if—and I had this eerie suspicion that turned out to be right—they were going to make some request of some kid: "Are you willing to be some blind person's roommate?" And I really thought that was an offensive—I didn't want them to do that. And in fact I was right. They did do that. When I found out about that, it made me even happier that I had done this.

02-00:55:14

Lage: So rather than just assigning you—if you had chosen a double room—they were going to be sure.

02-00:55:21

Asch: Right. And I couldn't stand that idea. And I think that was a good decision.
[telephone rings]

02-00:55:52

Lage: Well, that gets you to college. I wonder if we should stop here, if you're expecting that call right at 4:00?

02-00:55:57

Asch: Well, I have to make it in a couple minutes.

02-00:55:59

Lage: So we shouldn't get started on college, then. Let's do that tomorrow.

02-00:56:03

Asch: All right.

End Audio File 2 asch_adrienne2_06-19-07.mp3

[End of Interview 1]

Interview #2: June 20, 2007

Begin Audio File 3 asch_adrienne3_06-20-07.mp3

03-00:00:06

Lage: Okay. Today is June 20, 2007, and today we're at Yeshiva University, in Adrienne Asch's office, and I am Ann Lage, interviewing Adrienne for the Disability Rights and Independent Living Movement project. Adrienne, this is our second session, and yesterday we did a lot about family and early years, and we almost got you to college. I think we did get you to college. Tell me how you chose Swarthmore, and what you found when you got there.

03-00:00:43

Asch: Okay. I chose Swarthmore—I remember the March of 1963. When I was sixteen, I was at the same camp that I had been to for many years, and the camp counselor who met me that particular year was a woman named Bobbie Perkins—Barbara Perkins—who saw my classical music collection that I had brought to camp with me, and talked with me about politics, and said, "You should apply to Swarthmore." I'd never heard of Swarthmore. Nobody in our town had ever heard of Swarthmore. But that was because it was a crummy town. If you're in an academically knowledgeable area, people have heard of Swarthmore, but it wasn't an Ivy League school, and it wasn't a Big Ten university, and it wasn't the kind of place that most people knew about.

And my parents—my father wanted me to go to Brandeis. That's where all good liberal Jews went. But I didn't want to go to Brandeis, because it was full of only liberal Jews. And I was happy to have liberal Jews, but I didn't need an entire college of them. So I wouldn't apply. So I applied to Douglass, the state school, where my best friend had gone when she didn't get into Radcliffe and Oberlin. I applied to Radcliffe, where I didn't want to go. I applied to Oberlin—or, I was going to apply to Oberlin, but my parents didn't want me to, because it was founded by Presbyterians. And also, they weren't really eager for me to pursue a career in music, which they felt the chances of might have been heightened if I had gone to Oberlin, although I wasn't good enough, so it wouldn't have mattered. But anyway.

But I'd heard about Swarthmore, and I really liked it. It was a small, coeducational, liberal arts college. As my father pointed out amusingly, an hour and a half from Princeton, which was where Westminster Choir College was, which was where my high school boyfriend was going to college. I really fell in love with the place when I heard about it. It was very political. It was coed, which I wanted. It was a college, not a university, which I thought would be better. It was small, so I figured I could get to know people. And I liked that idea. It had a good music department, and it was very political. One of the things I really hadn't liked about high school was that I had so few people really interested in politics to talk to.

03-00:03:46

Lage: And here your parents were worried that you weren't interested enough in politics.

03-00:03:49

Asch: Well, no, they knew I was, but I was so involved in music that they were afraid it was going to swamp my political interests. So, that's how I picked it. I was thrilled to get into it.

03-00:04:15

Lage: Did your camp counselor—Bobbie—did she write you a letter?

03-00:04:20

Asch: I think she did. I think she did, and I think that may have helped, a lot. I think about that sometimes, sadly, because I didn't do very well there, and I hope I've let her know in other ways that I really appreciated it. I mean, I'm very glad that I went, and I'm very glad that I got in, and it was a really important experience, but I didn't do well academically. And that was very hard for me.

03-00:04:55

Lage: Now, when you say you didn't do well academically, you mentioned that you didn't feel your high school—or you found out that your high school wasn't such a good --

03-00:05:01

Asch: Well, I knew my high school wasn't a good high school. My senior year of high school, I had written an essay in my French journal about how we hadn't really ever been asked to think about anything in high school. We'd only be asked to memorize, and I was good at memorizing, and I could do that, but I had been asked very few essay questions where I had to give an opinion, or form an opinion about a work of literature, or a historical idea, or anything. I was quite anxious that I didn't really know how to do that. And I realized somewhere in my sophomore year in high school that if you could write a coherent paragraph, you were going to get an A, because there just were no standards. I mean, there was nothing being demanded.

03-00:05:50

Lage: So, what did you find when you got to college?

03-00:05:53

Asch: I was not ready. I mean, I was not ready. I had no self-discipline. I had no study skills. I'd never had to work hard, and I wasn't ready for 300 pages of reading a week, and twelve analytic papers in a semester. I didn't have the high school preparation, I didn't have the psychological stability, I didn't have the self-confidence because I didn't have the psychological stability. I didn't know whether I knew how to think. It had never been tested. I knew it had never been tested. And so I just procrastinated. I never finished anything on time, and I would talk in class, and some of what I would say was perfectly fine, but I was very intimidated by all these people who had read

Dostoyevsky, and read—you know, all kinds of things that I hadn't read, that I knew the names of, but hadn't read. [telephone rings]

03-00:07:31

Asch:

So, I procrastinated, I put things off. I mean, I would talk in class, and what I said was okay, as I say, but I was very intimidated, and I also really wanted to have a social life. I wanted to make a lot of friends. Even though I had been dating Win for many years, I was pretty sure that this was not a relationship for a lifetime, and that I wanted to meet someone who was more intellectually oriented, and more left-wing, and things like that.

03-00:08:06

Lage:

So how did you come to grips with this situation?

03-00:08:10

Asch:

Well, I didn't. I didn't come to grips with it. I struggled with it from the day I got to Swarthmore until the day I left. At the end of my freshman year, I had completed only two courses out of nine, because I'd been so anxious I couldn't finish any papers. So I spent the summer writing all my undone papers. I was very ashamed of myself. I felt I had let myself down, I had let my parents down, I had let the New Jersey Commission for the Blind down. It was interesting. One of my best friends from high school applied to Swarthmore for the following year, and I actually went to the admissions office and said, "You know, I know I'm doing very badly, but I don't want you to think that this other person can't do well just because I'm doing badly." And he didn't get in, and actually, I don't think he would have liked it all that well. Well, who knows? Anyway, he didn't go.

03-00:09:46

Lage:

Did Swarthmore have assistance of any kind for you?

03-00:09:50

Asch:

I didn't need any assistance.

03-00:09:52

Lage:

No, I mean in terms of academic coaching.

03-00:09:56

Asch:

No. No, they didn't have any. But the thing is, I didn't know what I needed. I mean, I probably needed massive therapy. Whatever the assistance I needed, it was very hard to put a name to it. I didn't know that I didn't have study skills, because I had never had to study. So I didn't know that there was such a concept. I didn't need disability-related assistance. I had all the readers, and tapes, and stuff. I wasn't always using them, because I was having too many long dinner conversations instead of reading my books.

03-00:10:55

Lage:

But were those long dinner table conversations important?

03-00:10:58

Asch:

Oh, yeah. Well, I mean, I made a lot of friends. I wasn't so miserable that I didn't make friends. I made friends. I started doing some political action kinds of things—nothing very extensive, but there was a Swarthmore Political Action Committee that was tied to the Students for a Democratic Society, and I did that, and I joined the Swarthmore College Chorus, and like many, many, many people who go to Swarthmore who are the top in their high school—well, you know, you put 1,500 kids—or actually 1,300, or whatever—who are the top in their high school together, and they're not all going to be the top.

03-00:11:47

Lage:

Right. And they're used to being the top.

03-00:11:49

Asch:

And they're used to being the top. So getting C's on your first papers, it was just crushing. And the problem was that I didn't exactly know what was wrong with them. I mean, if I did, it was easier. I could sort of figure out maybe how to do it better. But I didn't, really. It's not that professors didn't try to explain, but it's actually hard. I mean, now being a person who grades papers, it's very hard to explain why a paper is good. Very, very hard. You can talk about structure and writing, but it's not that I didn't write coherent sentences, or know what a paragraph was, it's just that they didn't have very much content, because I didn't know what kinds of things I was supposed to write.

Anyway, Swarthmore was a very important experience, and in many ways, a very good experience, in that I had the kinds of friends I wanted. I got to be in the most amazing intellectual atmosphere I'd ever been in. I did learn plenty when I was not so neurotic that I couldn't focus on what was going on in the class. I really met some wonderful professors, who were very inspiring in terms of being fabulous human beings and great intellects, and showing me that you could be an intellectual, and a politically engaged person, and a good human being, which I didn't have any reason to think that you couldn't, but I didn't know that many people. I mean, my father and the father of one of my friends from camp were probably the two most intelligent and intellectual people I knew, but my father didn't have a PhD, and my father hadn't finished college. My father was a very self-taught person, and there were huge gaps in his own education. He had no skills to offer in terms of how to teach me whatever it was I didn't know about buckling down and serious work, because he'd never done any, either.

03-00:14:34

Lage:

You majored in philosophy?

03-00:14:36

Asch:

Yeah.

03-00:14:37

Lage:

How did you happen to choose philosophy?

03-00:14:39

Asch:

Well, I started out to major in English or music. I wasn't very good at either one. I wasn't terrible, but I wasn't great. One of the professors of philosophy said, "Adrienne, let's—" In my junior year, when I was really very discouraged, I'd taken a lot of English, and a lot of music, and a lot of philosophy, and I felt I really didn't know what I wanted to do with my life, I really lacked a lot of confidence, because I'd been doing so poorly getting nothing better than a B, mostly C's, and just feeling very ashamed of myself, that I wasn't living up to my potential or my expectations that others had of me, or that I'd had of myself. I mean, I didn't really think the work was too hard. I thought I didn't know how to do it. And I think that was right. So Hans Oberdiek said, "Why don't we have you major in philosophy? You don't want to be a professional philosopher. You want to be a policy kind of person. Don't think of yourself as being an academic, but let's get you out of here with your sanity in tact." And that was a very kind gesture. It wasn't a paternalistic gesture, it was seeing someone who I think he was very fond of and saw potential in, but I was just a mess.

03-00:17:00

Lage:

Did you have a relationship with him where you did confide in him about your --

03-00:17:05

Asch:

Well, I didn't know—I mean, I confided in lots of people. I just didn't know—I was not silent. I wasn't suffering this in silence. All my friends, and anybody who knew me knew how unhappy I was. This was a bit of a problem too, but I didn't understand what the gap was between why I wasn't doing well and what I had to do, but it was not a gap anybody could really have explained.

03-00:17:46

Lage:

But you never—it sounds as if you never situated this problem in your blindness.

03-00:17:53

Asch:

No. Oh, no.

03-00:17:54

Lage:

And did others ever --

03-00:17:57

Asch:

Well, some people said, "Well, it probably takes you longer." Actually, in a very bad way, people would say, "Well, it takes you longer to get things done." And then I would say, "No, it doesn't. I'm just not organized," which was true.

03-00:18:09

Lage:

You knew better, the reason.

03-00:18:13

Asch: So, whenever anybody did situate it in blindness, that actually made things worse, because I knew that had nothing to do with it, but I didn't know what did have to do with it, and I didn't know how to get organized. People weren't in general situating it in blindness. They weren't just saying, "Oh, well, you're blind. You can't do better." They didn't really know what the problem was, and I didn't know what the problem was, either. I just knew I wasn't living up to my potential.

03-00:18:50

Lage: Nevertheless, you did graduate.

03-00:18:52

Asch: Well, yeah. It took a while. I changed majors. I took an extra year to complete my major. I was a very beaten down person by the end of that experience. I'd had a little bit of blindness discrimination at Swarthmore, not very much, and I knew that it was discrimination, but I also knew—I mean, there was one professor who didn't want me in his physics for non-scientists class.

03-00:19:40

Lage: Was he able to articulate why?

03-00:19:42

Asch: He just didn't want to do whatever he thought he would have had to do to help me understand the concepts. The music department also believed that a music major should be able to sight read a score—that if they put down a Mozart piano sonata, you should be able to play it looking at it. And one of the things that I realized—and this is also largely important to my later development—was that even though I perceived these things as discriminatory, I was doing so badly that I really felt I had no psychological tools, or intellectual tools, to go and say, "Look, you're really not being fair." Because so much that was going on was my own fault, that for this tiny thing—and it really was kind of tiny in the grand scheme of things—to be discriminatory, it was just—it would have been really stupid to cry discrimination when I just wasn't doing my job.

03-00:21:09

Lage: [laughter] I see. That's an interesting perception. But you were involved in SDS, you say. And was that focused on civil rights, or antiwar activity, or --

03-00:21:20

Asch: Both. Both.

03-00:21:23

Lage: And I guess one question we're always asking people is when did you begin to see disability rights as a civil issue?

03-00:21:30

Asch: Well, not then.

03-00:21:31

Lage:

But you didn't, at the time.

03-00:21:32

Asch:

No, because I thought that disability was just getting your books in Braille. I was not—still, go back to my, "Is it better to blind or black?" I still wasn't really experiencing discrimination. I was not doing my job. You know, nobody was stopping me from taking nine-tenths of my courses, or 95 percent of my courses, and professors were being very helpful in explaining things to me, and nobody was putting any obstacles in my way, except for the ones I was putting in my own way.

So yes, the music department was not very nice, and actually, at the end of my last year in the music department, one of the professors commented—said to me that he owed me an apology, and I said, "Yes, you do." And so, I certainly had been hurt by that. What I felt—and I believe this absolutely profoundly, thirty-seven, thirty-eight years after I graduated—95 percent of my problems at Swarthmore were my problems. They were serious problems. They were neurotic problems. They were not blindness problems.

03-00:23:14

Lage:

They were educational problems—preparation?

03-00:23:17

Asch:

Well, it's interesting. Three of my best friends from that era were women with actually quite similar psychological problems. They had much better educations, but we had the same inability to finish things, inability to make decisions about what we believed. We would read ten different views of a philosophical argument or a literary work, and we couldn't decide which one was the view we held, or we would feel that we hadn't read enough so we could never finish the paper, because we could always read more, or think more, or do more. And those three people—who are still people I know quite well—probably would say that they've only partly mastered these same issues in the last thirty-seven years. They're really a complicated set of psychological problems.

They were exacerbated in my case, I think, by poor academic preparation, by not being the child of a professional. I mean, one day, I was with a group of us who had gone to a Model UN event in North Carolina, and we were driving back to Pennsylvania from North Carolina, and we figured out that all of us were the children of parents who hadn't finished college. Well, that was a reveal-- we were all white. This was not about minority cultural deprivation, but at Swarthmore, if you were not the child of a college graduate, you were in a minority. The other three—these men that I was driving back to college with—did extremely well. I mean, they did much, much, much better than I at Swarthmore, but we all discovered a sort of exciting moment of commonality, of realizing that we were different from lots of the people around us in not

having that kind of cultural capital, if you want to call it that, in our upbringings.

Now, as I say, they were very, very talented students, and I think all three of them went to Harvard for graduate school and law school, and they did very well. So, they didn't have some of the neurotic problems I had, but they—when you put together a very mediocre high school, people sometimes being too willing to assume that blindness was a problem when it wasn't, so that I couldn't really get a hold of what the real problem was, because all I could tell people was that they were wrong. I wasn't slower than other people. Well, I actually might have been reading more slowly than some people, but in order to have figured that out, somebody would have had to say to me, "I can read this book in two hours, how long does it take you?" That's what someone would have had to say, and then I would have said either it took two hours, or three hours, or five hours, or—I would have had to have a very concrete example of how long does it take the average sighted person to read something, or do something, and then I could have said, "Well, how long does it take me?" But people in their sort of sweet way of saying, "Well, it just must take you longer." That would just drive me crazy, because I had no information that it did take me longer. Are you following me?

03-00:27:17

Lage:

Yeah. No, I understand, and I think with a sighted person, you'd find a range of two hours, four hours, six hours to read the same book.

03-00:27:27

Asch:

Right. So, the point is it wasn't obvious to me that it was taking me longer. It might have, but—and the SoundScriber records on which many of the books were recorded were terrible recordings. They skipped, and they were very, very—I mean, they were low fidelity, and they would skip, and then they would repeat. I mean, they weren't very good reproductions. Tapes were much better, but I started used tapes. So, I mean, I had very little excuse for doing poorly that was related to blindness.

03-00:28:02

Lage:

Were all the books available on tape, or --

03-00:28:05

Asch:

Either they were available or I got them recorded. There was no blindness issue to speak of. Other people who I knew were doing perfectly fine at college—who were blind. I mean, I didn't know that many, but the ones I'd gone to camp with, they were doing fine. There were some other blind students at Swarthmore. Some of them were doing fine. Some of them weren't. Anyway, as far as I'm concerned, then and now, blindness had almost nothing to do with my problems, and a great need of psychotherapy had a great deal to do with my problems.

- 03-00:28:53
Lage: Which came later, it seems.
- 03-00:28:55
Asch: Which came later.
- 03-00:28:57
Lage: What about career goals? What's --
- 03-00:28:59
Asch: Well, that was also unclear. The same things I wanted to do when I went to college, I still probably wanted to do. I wanted to be a counselor, or do some sort of civil rights work, or be some kind of journalist. But by the end of college, I didn't have a clue what I wanted to do, or what I could do. But again, that wasn't about blindness; that was about that I had done so poorly by my own standards.
- 03-00:29:33
Lage: Nevertheless, you graduated from Swarthmore.
- 03-00:29:35
Asch: Well, yeah. I graduated from Swarthmore, but --
- 03-00:29:38
Lage: And later got an honorary degree, I think.
- 03-00:29:40
Asch: Yeah, well, that's another matter. But let me say—I can say a little bit more. There were other blind students at college, some of whom I knew—well, I think I knew them all. I didn't either go out of my way to meet them or not go out of my way to meet them. One of them I liked a lot, one of them very much didn't like. He was this really Republican, conservative—he was one of the unusual Republican conservatives at Swarthmore. One of them I thought was a kind of very timid—very, very, very smart, but very timid, frightened person. There were a couple of other people with other disabilities: somebody who had had polio, somebody who was of short stature. I didn't know them well, but I knew them.
- 03-00:31:00
Lage: Did you see any commonality with --
- 03-00:31:03
Asch: No. I didn't either like them or not like them. The person who had polio was someone I actually liked quite a lot. The person who was of short stature I didn't particularly like. These were people a few years ahead of me.
- 03-00:31:35
Lage: Some people mentioned actually trying to avoid other people with disabilities.
- 03-00:31:41
Asch: No, I didn't.

03-00:31:42

Lage: You didn't.

03-00:31:42

Asch: No.

03-00:31:43

Lage: You just took people as individuals, it seems.

03-00:31:46

Asch: Right. I mean, I certainly didn't want people to say, "Oh, well, there's this other blind boy in the class, you must want to go out with him." Every now and then somebody would say that, and I'd say that was stupid, and I said, "I don't like Dana. He's not a very nice person."

03-00:31:59

Lage: He's a Republican.

03-00:32:00

Asch: Right. But if he needed a Braille writer, I'd give it to him, or if I needed a Braille writer, he'd give it to me. I mean, there was no—I didn't avoid him, I didn't avoid people, I didn't not avoid people. I'd had friends from camp who were blind, so it was no—and Tom Large [spelling?], who was a couple of years ahead of me, I liked very much when I met him, and he actually had a little bit of sight, and had never had recorded books, and had never had any services related to blindness, and I said, "Tom, you know, you're really straining very hard to read print, and you might want to get stuff on tape, and it would be much easier for you than getting headaches all the time." And I think he subsequently did, and has gotten services at various points. He's a terrific guy. I don't see him very often, but I am occasionally in touch with him, and he's a really fine person.

03-00:33:07

Lage: Did the school have anybody to facilitate getting the things recorded?

03-00:33:11

Asch: No, but we didn't—no.

03-00:33:14

Lage: You just did that on your own?

03-00:33:16

Asch: Yeah. I mean, I'm not a big believer in disability services offices. I think they're often very paternalistic and agency-like in the worst ways. I mean, they may facilitate some things for some people, but you could get your list of books that you needed ahead of time from the professors, and you sent them to Recording for the Blind, and they recorded them.

03-00:33:40

Lage: And was there a charge for that? A fee?

03-00:33:42

Asch:

No. You had to buy two copies of the book, and they paid you back for one copy, so you never paid more than whatever the other people were paying for their books. And the New Jersey Commission for the Blind paid a certain stipend a month for reader money, so I had money to pay readers for things. I had a Braille writer. I had a typewriter. We'd have a final; I would take it in my room. Blindness—again, I didn't need all this—quote—"assistance" that everybody thinks you need. I mean, maybe if I'd been trying to major in complex mathematics, or something --

03-00:34:35

Lage:

Lab science.

03-00:34:36

Asch:

Yeah, but again, people were doing that sort of thing then. I mean, go meet Geerat Vermeij, who is the MacArthur winner who graduated from Princeton, I think the same year I graduated from Swarthmore, and went on to get a PhD in marine biology—totally blind. I mean, you could do it. I'm not saying because one person did it that things shouldn't be made easier for people. I'm just saying some of the claims about how much you need are just overstated. You need your books in Braille—or you need your books in a form you can read, whether it's Braille, or tape, or computers, or whatever—and you need to be able to write, and you need to have professors who will let you use the alternative techniques that you have to use to do your work, but as long as nobody's stopping you, it's not that hard to succeed in college.

But I still felt—as badly as I did at Swarthmore, and as mixed up as I was at the end of it, and as uncertain of what I was going to do next, I had made friends, I had done some politics. I wasn't going to go to graduate school, but there were other people who weren't going to go to graduate school, and I decided I was going to move to New York and get a job in the world of nonprofit arts or nonprofit politics. I mean, I was going to do—and this was 1969 --

03-00:36:34

Lage:

A very political year.

03-00:36:35

Asch:

-- and this was the beginning of disability as a political issue, because start--

03-00:36:46

Lage:

For you, you mean?

03-00:36:47

Asch:

For me. Starting in August of 1969, I got the newspaper, and read all the want ads—either my parents read them to me, or I hired people to read them to me. I don't exactly remember. But I read hundreds of want ads, and I had a resume, and I sent it to various places. I didn't put blindness on my resume,

because I didn't think there was any reason to put it. I put what I had done, but as a college kid, you haven't done that much.

03-00:37:23

Lage: [laughter] Right.

03-00:37:24

Asch: But I had put some of the things that I had done, and I started going to job interviews. Oh, hold on. Let me go back. Two things. All during my college years, I did this choir and orchestra stuff that I had been doing during high school. I would come home every summer and work on this choir and orchestra. It was a very good choir and orchestra, and we created it ourselves, and I was very involved in the creating, and managing, and organizing, and publicizing of this. We hired the conductor, we planned all the publicity, we set up the concerts, and so I got a lot of organizing experience just running this little organization that we created. Okay.

And in 1967—the summer after my junior year—I also got asked to be a counselor at the same camp for the blind that I had been a camper at, and be a music counselor, as many blind people often were. I think the person they had picked for some reason couldn't do it, sort of at the last minute. And so even though I really didn't want to do it, because I was managing this choir and orchestra, I said I would, on the condition that I would be allowed to leave two nights a week and go to rehearsals. So I set it up that I did all the managing of the choir and orchestra while I was the music counselor at this camp, and that was a very interesting experience. I liked it. I liked the kids. I didn't like—I remember we had to write little reports on the kids to the New Jersey Commission for the Blind, and I wrote these reports. One of the things I didn't like was that I could see that because kids saw me there, instead of talking their problems out with sighted counselors—which is most of the counselors—they talked to me. I didn't think there was anything wrong with talking to me, but I thought it was wrong to assume that I had better answers, or more answers, or was more mature than many other people there, because I wasn't.

03-00:40:17

Lage: But they felt an affinity in some way, or an expectation that you would understand.

03-00:40:22

Asch: Yeah. Well, and the thing was, I didn't think that was untrue, but I also thought it was equally important for them to realize that other people could understand them, and that I felt they were sometimes not discovering how many other people were there who could understand them. So that was the first time I'd ever been a—quote—"role model," and I didn't like it, or at least I had mixed feelings about it. It's not that I didn't like the kids, or didn't want to help them, but I also felt that they were neglecting some of the other really fine people who were there.

03-00:41:09
Lage: How old were you then?

03-00:41:11
Asch: Twenty.

03-00:41:11
Lage: Twenty.

03-00:41:16
Asch: And—well, just that. Just that.

03-00:41:31
Lage: That also seems to be—aside from the point you're making—part of the experience that made you think about [working in] nonprofits in the arts.

03-00:41:39
Asch: No.

03-00:41:40
Lage: No?

03-00:41:40
Asch: No. The thing that made me think about nonprofits in the arts was running this choir and orchestra. The camp was just a kind of diversion. I mean, I did the camp because to some extent my parents said, "You owe this to other blind kids. You owe this to the community." I didn't entirely like that notion, but I feared it was some way of—I don't know—I didn't like notions of being a professional Jew, or being a professional—It was more kind of box-like stuff. But I did like the experience, and I did like the kids, and I found it kind of bizarre to be a role model to anybody, because I was such a mess, and I was so screwed up, and I knew it. And I tried to say, you know, "Don't look at me. I'm at college, but I'm not doing very well. There are a lot of things wrong with my life, so don't think I have it all figured out. I don't have it all figured out." But I suppose I had some things more figured out than they did, because I was seven or eight years older than they were, or six years older, or whatever. Okay.

So I read all these ads, and I started applying for these jobs, and I took my Braille writer with me to the interviews, so that I could take dictation and type it, and I was applying for the kind of job that women—smart women—applied for: entry-level kind of administrative assistant jobs in nonprofit organizations: The American Civil Liberties Union, the National Council of Churches, Clergy and Laymen Concerned, the Ford Foundation. I applied for a bunch of civil service entry-level jobs in civil rights agencies with the city of New York, or the housing office of the city government, or whatever. I didn't apply to anything in a bank, or anything in an insurance company. And then I applied to some arts organizations, Young Concert Artists.

They all had openings. I wasn't applying for jobs where there weren't openings. And I would go there and first of all, they were surprised that I was blind, and I'd say, "Well, yeah, okay. I am." And they would say, "Well, I don't understand, how are you going to do this job?" And I'd say, "Well, you have typing for me to do. If you dictate it, I'll type it, or if you dictate it into a machine, I'll type it, or if you write it out, I'll hire a reader, and bring the reader to the job, and then they'll read it to me, and I'll type it." I mean, I had reasonable enough answers, although the truth was I was making up a lot of my answers as I went along. How was I going to file things? I was going to put Braille labels on the files.

At some point, I remember calling up the New Jersey Commission for the Blind, and I had heard that there was a British system of Braille shorthand, so I called up the New Jersey Commission for the Blind, and I said, "Could you tell me about where I can learn Braille shorthand?" And they said, "Well, we never heard of Braille shorthand." I said, "Well, I know that people in Great Britain use it." They said, "Well, why don't you get your employer to use a Dictaphone?" I said, "I don't have an employer yet." "Well, why don't you become a rehab counselor?" I said, "I've never had a job! How am I going to become a rehabilitation counselor for somebody else? Just so I can show them how to become a rehab counselor?" And I slammed down the phone. I was so pissed. I thought, "These people are crazy!" And these people are the people who had said, "Go to college. You can do anything." And then they were telling me they didn't know about Braille shorthand, they didn't know how to help me get a job, they thought I should be a rehab counselor so that I could train other people to be rehab counselors, and I thought this was the stupidest thing I had ever heard. So I was really mad.

And then I went to the state employment agency that handled entry-level professionals, and I remember walking in to the entry-level professional interviewer, and the entry-level professional interviewer said, "Miss Jones isn't here." I said, "Well, I don't have an appointment with Miss Jones." "Yes, you do." "No, I don't. I have an appointment with you." "Well, she's the person who sees people like you." I said, "You mean entry-level professionals?" "No. She sees blind people." I said, "That's not who I'm here to see. I'm here to see the entry-level professional person." She said, "Well, you certainly know what you want."

So my forged disability identity came in the hundred job interviews I had between the beginning of August and my getting my first job in the middle of September of 1969, and one of them was a job that I applied for at Lincoln Center in the Education Division, and this was very important, because it was a job setting up concerts in public schools, and doing a whole variety of things that were very similar to the work I had done for seven years, and I had more qualifications to do that work than many young people, and I had a letter from a conductor who had conducted at Lincoln Center, to say that I had done this work. So I applied for the job, I got an interview with the personnel office.

The personnel office said, when I showed up, "Well, you didn't tell me you were blind." And I said, "No." And he said, "Well, I guess that's probably true, because if I had known you were blind, I would not have let you come, so maybe you were right." And I said, "Well, I guess that's probably why I didn't tell you, but I also didn't think it was important." And he said, "Well, you've convinced me, but now I have to get Jane Norris—" Or whatever her name was; it wasn't Norris, it was Norton or something. "—to interview you. If she's willing to interview you, that's fine." So, he called up this person, and I think he told her that I was blind, and she refused to see me. And I said, "I'm not leaving this office until she sees me. She doesn't have to give me the job, but she has to talk to me." So, the place closed. She wouldn't see me.

03-00:49:19

Lage: You held a sit-in, basically.

03-00:49:22

Asch: So I came back the next morning with a letter to the vice president of Lincoln Center, and I said the same thing. She refused to see me. And then I called the Equal Employment Opportunity Commission, and I said, "I want to file a civil rights complaint." I said, "I've been turned down for an interview for a job, based on blindness. And they said, "Well, you can't file. There's no law that protects you based on blindness." This was 1969.

03-00:49:58

Lage: And you kind of assumed that that would be covered, along with other discriminatory acts.

03-00:50:04

Asch: Right. Well, I just stood there, sort of like, "No. This can't be happening." So, then I called the State of New York Commission, and there was no law. So, then I called the City Commission on Human Rights, and there was a law, and I filed a complaint. And then the City Commission did an investigation, and the way they investigated the complaint was they sent my complaint to Lincoln Center. Lincoln Center sent back a job description, telling them why I couldn't do the job, as described in the job description, and they closed the case. And then I saw the job description, and I said, "First of all, this isn't the job description I was given, and second of all, I can do the job in the job description. You just think I can't, so you obviously don't know how to investigate cases."

I was one furious, demoralized person, but the good thing about all that fury was I didn't know how to write a philosophical paper, but I knew how to do this job, and I knew how to do all the hundred jobs I had applied for, and the big corporate organizations said, "Oh, you'd have such an easier job in a small one." And the small ones said, "You'd have such an easier time in a big one." And all of them were being very sweet, and they were all not giving me jobs. And I was really upset, and really worried, and shocked—utterly shocked—because I had expected a certain amount of bullshit and discrimination, but I

had a perfectly good job history for somebody coming out of college. Most kids didn't have anything much better. I was smart. I could type.

People would say things like, "Well, the elevators don't—they just light up when you get on them, and how are you going to know whether it's an up elevator or a down elevator?" And I'd say, "Well, if it's an up elevator, I'll go up. And if I want to go down, I'll press the down button." I mean, nobody was asking me anything I actually didn't have a fairly reasonable answer for. So, unlike Swarthmore, where nobody was stopping me and I couldn't do what I was asked to do, all kinds of people were stopping me. They were completely stupid and wrong, and I could do what they wanted to do, and this was straight out discrimination, and I knew it.

03-00:52:49

Lage:

And you saw it so quickly and dramatically.

03-00:52:52

Asch:

Right. And it was—I mean, in a way, it was a relief, because instead of being neurotically miserable because I couldn't write English papers, I knew this was just plain wrong.

03-00:53:03

Lage:

[laughter] Yes. That's great.

03-00:53:07

Asch:

Why are you laughing?

03-00:53:08

Lage:

I just think it's a delightful story, in a way. From the angst of college to really getting a grip on something like this.

03-00:53:21

Asch:

I mean, I didn't exactly—and it also became clear, once I discovered there was no federal law, and once I discovered there was no state law, and once I saw that the New York City Commission didn't know how to investigate a case, and in effect just reinforced discrimination, I thought, "Well, if I don't change the law, I'm never going to get a job."

03-00:53:46

Lage:

But there was a New York City law. How did --

03-00:53:49

Asch:

Yeah, but that's the point. They didn't know how to implement it. They had done an investigation that was a joke. You can't investigate a case that way. You can't send the employer a complaint, get a description back from the employer, and close the case. That's no way to investigate a case.

03-00:54:12

Lage:

So tell me where this led.

03-00:54:15

Asch:

Well, it led to a lot of things. I mean, first of all—and a friend of mine said, "Adrienne's twenty-three, and she's just discovered that she's blind." And in a certain sense, that was right. I mean, because it was the first time I realized that disability was a political issue, and that I wasn't going to solve my problems if I didn't get political. And I knew how to get political. I'd done antiwar things, and I'd done civil rights things, and now I was going to have to do disability rights things, and I didn't like it, but I was going to do it.

So, then a couple of other sort of complicated coincidences occurred. One of my roommates in my apartment in New York, was working for a then-classical radio station, WRVR, the radio station of the Riverside Church, which was a pretty political radio station, and a classical music radio station. The Riverside Church was doing these readings of names of the war dead, as part of working against the war. So she came to me and said would I work on putting the names of the war dead in Braille so that blind people could read, and I said, "Sure." She said, would I help organize a day of blind readers? And I said, "No, but I'll put the names of the readers in Braille. I think it's stupid to have a day of blind readers, just put the names in Braille and let people read." And she said, "Well, but the thing is, we want to publicize that we're doing it, so we need to have a day where everybody who's reading is blind, and then we'll publicize it, and then people can read any old time they want." So I said, "Okay," and she said, "There's somebody who will help you do this."

Well, the somebody who would help me do this was somebody who was a graduate student at Columbia, six years older than I, who had finished college at Harvard in 1963, who was blind also, named Pat. When her friend went to him to ask him if he would do this publicizing of putting names of the war dead in Braille, he said more or less the same thing I said, which is, "No, I won't have a special day, but I'll put the names in Braille." But then, anyway, they got each of us to see the point of why they should have this special day, so we agreed to put the names in Braille and get blind people from the city to read for one day, and then the names would be there for anybody who wanted to read.

So that got me in touch with Pat, and several other blind people in New York that I didn't know. Pat was six years older than I. He was blind. He was finishing a PhD in political science. He was married at the time that I met him. He subsequently ended his marriage. We eventually got romantically involved and had a very complicated and tumultuous relationship for ten years, but he was someone who had the musical—he was a very good pianist, and a very good singer, and was involved in SDS [Students for a Democratic Society] kinds of things, and at Swarthmore, actually, an interesting thing was that I was involved in political things and musical things, but there was only one other person who was interested in both classical music and serious politics, and so I'd always been looking for musical, political people. I'd always had friends who were musical and friends who were political, but I'd never had

very many friends who were both. And so there was Pat. He was musical. He was political. He was very successful, and smart, and charismatic. He was blind. Obviously had figured out how to—he was getting a job in political science as a professor.

03-00:59:59

Lage: I'm going to stop you right there, because we're coming to the end of the tape, unfortunately.

End Audio File 3 asch_adrienne3_06-20-07.mp3

Begin Audio File 4 asch_adrienne4_06-20-07.mp3

04-00:00:04

Lage: Okay. We were talking about Pat, and --

04-00:00:08

Asch: All right. So I'm --

04-00:00:10

Lage: Do we want to get Pat's last name, or...

04-00:00:12

Asch: Peppe. P-E-P-P-E. So, together, we did this reading of the names of the war dead, and organized other people, and then we joined the National Federation of the Blind, and I realized that all those things I'd read about Jacobus tenBroek, and all those student council presidents who couldn't get safety deposit boxes, and all the discrimination—I suddenly realized that he wasn't kidding. I'd had a charmed life, but I'd stopped having a charmed life.

04-00:00:54

Lage: Had you continued to read Jacobus tenBroek?

04-00:00:59

Asch: No. I mean, I had just read it in the *Jewish Braille Review*. It hadn't been --

04-00:01:04

Lage: It hadn't been something you followed, or --

04-00:01:05

Asch: No.

04-00:01:07

Lage: So, you joined the National Federation for the Blind --

04-00:01:10

Asch: *Of* the Blind, please.

04-00:01:11

Lage: Of the Blind. Pardon me.

04-00:01:13

Asch: Very important.

04-00:01:14

Lage: Yes, I can see that.

04-00:01:18

Asch: And a book came out at the same time by Robert Scott, called *The Making of Blind Men*, and we read it. It was about how agencies for the blind—service agencies—created stereotypic people, who couldn't live in the world. And also, I mean, the other thing that was going on, I'd finally gotten a Dictaphone typing job at the Anti-Defamation League of B'nai B'rith, which was a nonprofit agency. It was the only agency that would hire me. In many ways, it was a terrible job, but at least the memos I was typing from dictation were about things that interested me. First of all, they treated women very, very badly there. All the women were called by their first names, and the men of the same age were called, "Mister."

04-00:02:30

Lage: And did that strike you right away?

04-00:02:31

Asch: Oh, yeah. Wasn't hard to miss. And there was a clear professional distinction: I started to get to know some of the professional research assistants, and it was made clear to me that as a typist, I shouldn't eat lunch with them, or get to know them, because I was only a typist, after all. And I didn't have any use for that. And I was treated—you know, the typists didn't like me, because I wasn't a pure—I wasn't a lifetime typist. And the research assistants—I wasn't a research assistant. And so here was this agency that was fighting anti-Semitism, and various forms of discrimination, and treating most of its workers like shit. But it was a job, and I was living in New York, and I had an apartment with my friends, and I was doing other kinds of political things, and doing classical music kinds of things. So, even though I didn't like this job, I liked being in New York, and I liked not having homework all the time, and being behind. I mean, it was the first time in all those years of Swarthmore, that I wasn't behind, and I didn't have things hanging over my head. And so Pat and I got involved in the National Federation of the Blind and read things about and by Jacobus tenBroek, and he had died just a couple of years before, but he really was a great orator, and his speeches were wonderful, and it was very exciting, and then --

04-00:04:40

Lage: Was his memory kept very alive there?

04-00:04:44

Asch: Oh, yeah. Oh, yeah. Absolutely.

04-00:04:46
Lage: What did getting involved in the NFB mean? What did you do?

04-00:04:51
Asch: Well, first we went to some local chapter meetings, and then we formed a chapter of New York people, and --

04-00:05:05
Lage: So you formed a new chapter?

04-00:05:07
Asch: Yeah, because we didn't like the one that existed. It wasn't doing anything. So we formed a chapter, and one of our activities was Brailleing the WBAI program guide, for example. The BAI was the listener-- the New York version of KPFA. There wasn't public radio then. This was listener-supported, noncommercial, radical radio.

04-00:05:32
Lage: Pacifica-type --

04-00:05:34
Asch: Yeah, it *was* Pacifica.

04-00:05:35
Lage: It was Pacifica?

04-00:05:36
Asch: Right. So we Brailled the program guide. That was one of our activities. And I forget what other kind of things we did --

04-00:05:44
Lage: Anything relating to job discrimination?

04-00:05:46
Asch: Well, I'm getting there. I'm getting there.

04-00:05:48
Lage: I'm sorry.

04-00:05:53
Asch: And I said, you know, having had this experience with the New York City Commission on Human Rights, and having discovered there was no state law, and no federal law, I said, "We should solve this problem." So we started in 1972 to organize—well, no. Let me go back. In 1971, I'd started social work school, and I'd had a lot of discrimination getting into social work school, but I got in. A professor of mine there, who was interested in blindness and disability issues, told me about Judy Heumann, and told me about this group that was meeting at the Eastern Paralyzed Veterans Association, on Park Avenue South, that was a kind of cross-disability organization. And so I went to meet her, and meet them, and get involved in cross-disability issues, because I had had so much discrimination in all of my job hunting, and in all

of my getting into school, that I'd seen just how much discrimination there was.

04-00:07:42

Lage: And did you see it at that point as --

04-00:07:44

Asch: Well, that's what I'm saying. Yeah. I mean, I knew it was discrimination --

04-00:07:48

Lage: But, I mean, did you see it as an issue broader than discrimination against the blind? Did something bring it to your consciousness?

04-00:07:53

Asch: Yeah. Well, I mean, if it was happening to blind people, there was no reason to think it wasn't happening to other people. When Irv Lukoff said, "You should meet Judy Heumann and Joe Mandela," I didn't think that was a foreign concept. And actually, it got me into trouble with the Federation in some ways. I was always perfectly willing to do cross-disability work, but I was also a feminist. So, I didn't see blindness discrimination as different from race discrimination, or sex discrimination, or any other kind of discrimination. So I started to work with Judy and the various other people in this cross-disability kind of movement, and I think I joined Disabled in Action, and I still worked with the Federation, and we did a picket of the accreditation agency that was accrediting organizations that served blind people, and it was a terrible accrediting agency, with terrible standards, and they wouldn't let blind people participate in the making of the standards, and so Pat and I and this other small little chapter of the National Federation of the Blind led the first picket in December of 1971 of that agency.

04-00:09:31

Lage: And did DIA --

04-00:09:35

Asch: No.

04-00:09:35

Lage: -- help you out with that?

04-00:09:36

Asch: This was just a blindness thing.

04-00:09:37

Lage: This was all blindness.

04-00:09:37

Asch: This was just a blindness thing of that one agency. And then starting in 1972, when I was going and doing all this cross-disability stuff, I said, "Let's create a civil rights law." You know, an amendment to the New York State law, to include people with disabilities. We found two legislators in the New York

State Senate and Assembly who were willing to sponsor the law, and so starting in 1972, one of my main activities, just as a member of the organizations, were to help draft the bill and work with the legislators to lobby for it, and try to get organizations to support it.

04-00:10:30

Lage: But it sounds like it was your idea?

04-00:10:32

Asch: Well, it was probably my idea. I mean, I think it would have happened anyway at some point, because when we put the bill into the legislature, there were other bills in the legislature saying some of the same things, but they weren't as good. So somebody had had the idea, but at that point, I got hold of all the other state laws that included people with disabilities, and I read them, and I saw all the things that were wrong with them—all the loopholes, and the things they didn't include, and so we tried to write a law that didn't have those loopholes, and then I went to all the civil rights organizations, women's rights organizations, the ACLU, and the agencies that served people with disabilities to try to get support, and it was really disgusting to see how few people wanted to support it.

04-00:11:28

Lage: Can you recall some of the reactions, or describe --

04-00:11:30

Asch: Well, the agencies said, "We help people through rehabilitation and employ the handicapped. We don't do this. We don't fight for civil rights legislation," and a group of us—Judy Heumann and I, and some other people, went to see Eleanor Holmes Norton, who was the commissioner of the City Commission on Human Rights, and we said, "You're not implementing this city law, and there's no state law, and there's no federal law." And she said, "Well, we need a \$1 million grant from HEW. We don't understand disability discrimination. It's not the same as other discrimination." And we said, "You don't need a \$1 million grant. We'll help you—for free." I had filed a second complaint there about how an employment agency refused to serve me. I'd gone to some employment agency, and they had sent a letter saying they couldn't serve me, because they didn't have Braille signs and—I don't know, some other really stupid thing—and again, the city closed the case, saying they couldn't serve me, and I said, "You never sent me the complaint to show you why this description is wrong. They don't need Braille signs. They don't need any of the things they say they need. You don't know how to do an investigation." And in some ways—I mean, I was very obnoxious, but I was right.

04-00:13:02

Lage: Of course. [laughter]

04-00:13:04

Asch: I mean, I was young, and in a lot of ways, I didn't know anything about how to pay my dues, professionally, but I was completely right. I have no problem

with thirty-five years later saying, "I was right. They were wrong." I have every reason—I might have learned how to be more polite, but it was hard to be polite. They were so incredibly stupid, and it was so obnoxious, and so constant.

04-00:13:41

Lage: Did any of these groups that you approached get it, or offer support?

04-00:13:46

Asch: Eventually. Eventually. By '74, when the legislation was in the legislature, we had some support. And by then, there was this group called the Policy in Action Conference for the Handicapped that had worked against the Willowbrook stuff, and I had met Doug Biklen. I don't know whether you've run across the name Doug Biklen, but this is an important name. And by then, in January of '73, a bunch of us went to Washington to protest the veto of the Rehab Act. By then, we had met Eunice Fiorito, who was in the Mayor's Office for the Handicapped in New York, who was trying to do some good stuff, although—I didn't like her very much. I mean, she was very bureaucratic.

04-00:14:57

Lage: Now, tell me more about her, because her name comes up a lot, and --

04-00:15:00

Asch: Well, I don't remember her very well. I mean, I certainly knew her. She was kind of very loud and impressed with herself, and acted as though—in some ways, acted as though she was the only smart blind person in the world, but nonetheless, she had this job, and --

04-00:15:22

Lage: And what did that office do?

04-00:15:23

Asch: Well, it didn't do much. But it was supposed to do a lot. I mean, it wasn't very clear what it did, but it did help these fledgling little disability rights groups with—let us use their phones, and organize, and helped us find other names, and served as a kind of meeting place for people to get to know one another, and so most of the people—there were various people at the state and city level in Disabled in Action, mostly people with mobility impairments—mobility disabilities. Mostly people using wheelchairs, but not exclusively. People involved in the deinstitutionalization movement, some people who were deaf—not too many—mostly around Judy Heumann, but Phyllis Rubinfeld was involved, and Anna Fay, and Shirley Morgenstern, and Pat Figueroa, and Bobbi Linn, and Denise McQuade. I don't know how many of these names you --

04-00:16:58

Lage: Some of these people, we have interviewed.

04-00:17:00

Asch: Marilyn Saviola, Kip Watson—some of these were a little bit later. But anyway—

04-00:17:18

Lage: What was Disabled in Action? What were projects like--

04-00:17:20

Asch: Well, I didn't spend a lot of—it was mostly people in their twenties, who had disabilities, who were fighting for the same kinds of things that needed to be fought for. They wanted jobs, and they wanted an end to discrimination, and we wanted to get passage of the Rehab Act, and—it was Judy. It was Judy and her friends.

04-00:17:47

Lage: Tell more about Judy, from your point of view.

04-00:17:51

Asch: Well, Judy was a dynamo. She was funny, and smart, and energetic, and she had created Disabled in Action, and I was very glad she was there.

04-00:18:13

Lage: She's often given credit for sort of seeing the cross-disability connections --

04-00:18:20

Asch: Yeah, well.

04-00:18:20

Lage: -- maybe earlier on than others.

04-00:18:23

Asch: Well, she did. ACCD was formed in 1974, so she wasn't the only person to see it. If there's one person with a disability who probably deserves more credit than any other, I would say it's Judy. I think Mary Lou Breslin is fabulous, and might be smarter, and might be more hard working, and is one of the most—I mean, she's fabulous. And Pat Wright is really good, and there are lots of really good people. But I think Judy, by her charisma, and her energy, and her twenty-four hour a day, seven day a week, absolutely unstoppable commitment—you know, she's amazing. She's totally single-minded.

I mean, one of the things that was very clear to me was I was not willing to be quite that single-minded. I was willing to devote a lot of energy to getting a civil rights law passed that included people with disabilities, and I was really excited about it, but I wanted to do other things. I had other friends, I wanted to do music, I wanted to do other kinds of politics. That wasn't the only thing I wanted to think about, and for a lot of people—not everybody—but for a lot of people who were doing disability rights, who were in our twenties, who had either had disabilities most of our lives or become disabled in accidents, or—like Debbie Kaplan, or Ralf Hotchkiss, whose names you probably know.

04-00:20:33

Lage: Yes.

04-00:20:34

Asch: All right. So, Debbie and Ralf each acquired disabilities when they were in their teens. Okay. So you had a lot of people in their teens and twenties acquiring disabilities, becoming active, because they would have been active in something else, if they hadn't become disabled. For a lot of people like Judy, who certainly saw connections to women's rights, or racial issues, or whatever, disability was the most salient thing in her sense of herself. It wasn't just that people treated her a particular way. She did see disability as formative. Harilyn Rousso saw disability as formative. Phyllis Rubenfeld saw disability as formative. I'm still prepared to say that I didn't. Maybe I should have, but I didn't.

04-00:21:33

Lage: Even though you had also had disability from birth.

04-00:21:38

Asch: Right. I acknowledged it. It's sort of like, "Yes, okay, I'm blind. If you're going to treat me like shit, I'm going to fight you." But I don't think it's any accident that several of us were Jewish, that several of us were also feminists, or men—the leaders were white, middle class, sometimes Jewish, upwardly mobile people. It's sort of like what I said in "Personal Reflections." We grew up believing if you worked hard, this was a meritocracy. You could make it in America. And so when we found out we couldn't, we were angry.

04-00:22:37

Lage: And indignant.

04-00:22:38

Asch: Right.

04-00:22:40

Lage: Most of the people you mentioned were women. Now, do you think that's significant?

04-00:22:43

Asch: Well, I think that some of the men were as talented as some of the women, not all. I mean, Pat Figueroa and Ed Roberts, obviously, and Jacobus tenBroek, and Kenneth Jernigan. A lot of men, though, if they went on, and got a higher education, and got a professional degree—this was interesting about Pat. Pat [Peppe] did get involved in disability issues for a while, but because he had his PhD and had a job, in some ways, he had already accomplished what he wanted to accomplish, so that yes, he'd had a certain amount of discrimination, but he had the tools, and he had the skills, and he'd gotten a job. So even though there was discrimination, and even though things weren't as simple, maybe, as they should have been, and he had stupid things said to him at job interviews, he had gotten a job, and it was clear to me that if I'd

gotten a job when I first got out of college that was a reasonable job, that would have been fine.

I don't know whether I would realized how much discrimination there was, because if I hadn't had it, I still would have believed that if you were black, you were discriminated against, but I wouldn't have known how much disability was an issue. But it didn't take very long once it was thrown in my face for people to say, "Hey, wait a minute. This is bad." And so I devoted a great deal of my non-work and non-school time between 1970 and 1974 to getting this human rights law written and passed, and then it did get passed, and I had finished graduate school, I had a social work master's, and I applied for jobs—and this was interesting—I applied for jobs when I got out of social work school, and this time, I had six job offers. Three of them in disability-related jobs, that I didn't particularly want—I mean, they weren't awful jobs, but I didn't really want them—and three of them in quite interesting jobs. I went on lots of job interviews, and people said some pretty stupid things, and I had some professors who insisted on writing letters of recommendation that were all about my blindness, and I said, "Well, then, you can't write me a letter of recommendation, because you either have to believe I'm good enough to get the job—" I mean, I had a lot of discrimination in social work school.

04-00:25:54

Lage:

Tell me about that.

04-00:25:56

Asch:

Well, first of all, they made me go through a special interview that they didn't make other people go through. I had a fieldwork advisor who didn't want to work with me. I realized somewhere in the middle of the interview process that even though I'd been accepted, they weren't going to admit me if they didn't find a field advisor who was willing to work with me. And they'd had other blind people in their program. Eunice Fiorito, in fact, had been a graduate of their program seven or eight years before, but they acted as though every blind student was the first. I mean, it was really dumb. And the other thing that was kind of interesting was because I wasn't majoring in case work—which all the sweet little blind people were supposed to do, because we were all good listeners --

04-00:26:45

Lage:

Did you get that expressed?

04-00:26:47

Asch:

No, but there was some of that quality. I was majoring in community organization, and what I expected when I went on my interviews was why a white wanted to do tenant organizing in the South Bronx, or something. I mean, I expected to have conversations about race, but all they wanted to know was how could I travel, and how did I use a knife and fork—I mean, they were just utterly ridiculous. And I had professors who didn't believe I could do the work, and field advisors who didn't believe I could do the work,

but again, they were being so stupid that it was very easy to fight them, because there was nothing subtle. They were just wrong.

04-00:27:35

Lage: And did they accept it once you were able to show them, or discuss with them?

04-00:27:38

Asch: Pretty much. I mean, not entirely. There was one person who said, "You have to call up the field placement that we've picked out for you and tell them that you're blind," and I said, "I certainly will not." And they said, "Well, it's not fair." I said, "It's perfectly fair. This is a field placement. I want to do it. I can do it." The thing that was kind of funny—there was no law, and I knew it. I mean, I had no legal protection. So I could persuade and fight and argue, but I had no legal protection, and I knew it, and I said, "If you're going to call the fieldwork agency, you can do it, but I'm not going to do it." And I think that the guy did it, and they didn't tell me I couldn't come, although they were nervous. So I had to convince people, but it wasn't all that hard, because the things they were asking me to do weren't all that hard.

04-00:28:56

Lage: So, did you end up with a job in community organizing?

04-00:28:58

Asch: Yeah. Yeah. I got a job working for the city of New York doing health services administration work, and I had a choice among jobs, and I picked a job that I thought was going to be a good job for me. It might or might not have been the best job, but anyway, I picked it, I did it. [brief interruption] '73, '74, all right.

04-00:29:32

Lage: Well, those are important years. But anyway, we were talking about the experience of getting the job, and --

04-00:29:39

Asch: All right, so I got this job --

04-00:29:40

Lage: And social welfare school.

04-00:29:46

Asch: So, I got the job. And then my own hang-ups about work, and writing, and finishing things were right there, just as they had been before. They were there in social work school, too. So I hadn't solved all of my neurotic problems. I still had them, but at least I had a job, and it was a reasonable job --

04-00:30:18

Lage: Was it a field you saw yourself staying with?

04-00:30:23

Asch:

Well, I didn't know, but it was a completely reasonable job. I had no—I was happy I had picked it. I'd had more choices than I'd ever expected to have, I felt good about that.

04-00:30:43

Lage:

It was at the same time as all the activism, which is interesting, too. I mean, you're going to school, you're involved in the civil rights activity, and --

04-00:30:53

Asch:

Right. So, meanwhile, I was doing all this activism to get the law passed, and then when the law got passed in 1974 in New York State, and signed, I mean, it was a big thing. We were so happy. It was just—one of the most important days of my life was knowing that this human rights law had been passed, and we had a demonstration—we got around three hundred people from around the state, because Malcolm Wilson didn't want to sign the bill into law, and we had three hundred people—people from sheltered shops, people from all over the state. Blind people, people with other disabilities, and we'd mobilized them and gotten them together, and there they were, picketing out in the front of the capitol in Albany. It was a big deal, and then on June 15—the last day that he could sign it—Malcolm Wilson signed the bill.

04-00:32:09

Lage:

Do you have a sense of why? Were the demonstrations crucial in changing his mind?

04-00:32:13

Asch:

Well, I don't know that they were crucial, but they certainly got some publicity. And there were some other things—I forget. We picketed the New York State Division for Human Rights that didn't want to support the bill, and they had these cute little disabled people outside picketing, and the commissioner came out, and I forget—he was a very obnoxious kind of bureaucratic guy, and said he'd support the bill, and I think we said, "We want you to say that in front of a microphone, so that you can't go back on it." And I think we got some reporter there to get him to say that in front of a microphone, or on camera, or something. And we got it done.

04-00:33:18

Lage:

Were you happy with the law?

04-00:33:20

Asch:

Oh, yes. Because it was a good law. We had worked really hard to get rid of a lot of loopholes, so it didn't have a lot of things about how the employer could prove that somebody wasn't qualified. It did not exclude people with disabilities, any disabilities. It wasn't just physical disability. It didn't require that you use a crutch or a cane, to prove that you were disabled. It included any disability: visible, invisible, mental, psychological, physical. It included housing and public accommodations. It included everything that the law for everyone else included: housing, public accommodations, and employment.

And we were pretty sure it had gotten rid of most of the loopholes, and we were *really* proud of it.

04-00:34:30

Lage: Did the NFB work on that also?

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Asch: Well, I was the main person from the NFB.

04-00:34:35

Lage: At one time, just a few minutes ago, you said something about "That got me in trouble."

04-00:34:39

Asch: Well, that was later.

04-00:34:39

Lage: -- when you were involved with DIA?

04-00:34:40

Asch: That was later.

04-00:34:41

Lage: Oh, that was later. Okay.

04-00:34:43

Asch: After it got passed, and people from NFB in the state said, "You introduced yourself during this picket as representing not only the NFB but the Policy in Action Conference for the Handicapped," then NFB didn't like that, because they didn't like cross-disability work, and they didn't want to be involved with ACCD, and the American Council of the Blind was interested in ACCD, but they weren't.

04-00:35:18

Lage: Why—what are the roots of that attitude?

04-00:35:24

Asch: I don't entirely... I think there are two roots, one of which makes sense to me, and one of which is just parochialism and ignorance. The one that makes sense is that blind people are a very small—they're a very low-incidence minority—low-incidence disability—and in the general services for rehabilitation, when blind people were in the general rehab agencies for states, state agencies served people other than blind people, and so the blind people in general state services tended to get even fewer state services than people with other disabilities. There was also the fact that blindness had special exemptions that other people with disabilities didn't have, and they didn't want to lose them. Now, I don't necessarily agree with this. I mean, I don't think blindness should be treated for tax purposes or social security purposes better than other disabilities. I think if there are reasons for social security to have higher wage exemptions for blindness, they also should apply for people with

other disabilities. They don't. So I think people didn't want to lose the preferential treatment that they had under the Javits-Wagner-O'Day Act, under the Randolph-Sheppard Vending Act—blind people had some programs designed to serve them, and they didn't want to lose those programs, so they were very nervous about losing what they had in cross-disability work.

They also felt they would get less in cross-disability service agencies—you know, that it was easier to provide people with wheelchairs than it was to teach people Braille. And that's probably true. And it's probably cheaper. So, an agency will provide you with a manual wheelchair because it's a one-time thing, and it doesn't require teaching somebody Braille, who's newly blind. It requires other things. But then the rest of it, I think was just plain ignorance, and kind of stupidity of—or, not stupidity, but the kind of basic public prejudice that people had about blindness, they had about deafness, or mobility impairments, or mental retardation. I mean, unfortunately, the fact that people experience one kind of discrimination doesn't necessarily mean that you learn your lesson.

04-00:38:28

Lage:

From your reading of tenBroek—I know these speculative questions aren't good—but where do you think he would have stood, if he had lived a bit longer?

04-00:38:39

Asch:

Well, he wrote the law review article, "The Right to Live in the World,"² and that was an article about disability in general, so he certainly understood discrimination against blind people as part of a larger disability discrimination. He had worked so hard to found the National Federation of the Blind, and was so much struggling to get it up and running, and saw the value that it had in mobilizing blind people and giving people a sense of pride and camaraderie. I don't know. He might have said, "Work behind the scenes, but don't join coalitions." He might have said, "Join coalitions, but keep your separate organizations." He certainly would not have wanted the National Federation of the Blind dissolved, and that's fine.

I think he might have been more imaginative than Jernigan was. I would like to think he would have been. I think he was a more progressive person about civil rights, about women's rights. I don't know what he would have said about the Vietnam war, but his sensibilities were much more Berkeley than they were—you know. But he was a very strong-minded man, who had led more or less single-handedly the National Federation of the Blind, and I don't know.

² Jacobus tenBroek, "The Right to Live in the World: the Disabled in the Law of Torts," California Law Review, vol 54, no. 2, May 1966.

He might not have supported a cross-disability coalition. I think he would have. But he wasn't there. And Jernigan came out of Tennessee, had fought hard, had gone to a school for the blind, started life probably as a sexist, was definitely racist. I mean, unlearned those things—got much better over the course of his lifetime, but in the 1970s, he was a chauvinist, he was a racist. He believed in blind people, but he was a person of his times, and of his origins. He didn't have a kind of cosmopolitan upbringing. He had an uneducated set of farm parents. And he loved Jacobus tenBroek, and revered him, but he was his own person, and a very different person.

04-00:41:34

Lage: Did tenBroek kind of choose him as his successor?

04-00:41:41

Asch: Probably. Yes, probably. I think he saw in Jernigan a real orator, and a real leader, and a man of the people, and someone who could inspire, and who had a very big heart. Although he and I—Jernigan and I—didn't get along in the seventies, because I was much too left-wing. I mean, I was living with a man I wasn't married to. You just didn't do that. You certainly didn't do it publicly in the National Federation of the Blind.

04-00:42:15

Lage: Oh, really?

04-00:42:16

Asch: Oh, no, no, no. This was not a countercultural organization. This was not Berkeley. This was run by people from Iowa and South Carolina, who were as mid-American and Republican—in all of the ways you could be—as you could imagine. They were fabulous on blindness discrimination, but they were --

04-00:42:37

Lage: They weren't part of the counterculture.

04-00:42:39

Asch: They were not part of the counterculture. They were absolutely not part of the counterculture. They didn't want people picketing the Vietnam war. They didn't want to talk about abortion. They didn't want—I mean, they said, "Look, we're a single-issue organization. We're only interested in blindness. Keep your abortion issues, and your Vietnam war issues, and your living-in-sin issues out of here."

04-00:43:02

Lage: How did the national relate to the local chapter? It sounds like they were right on top of it.

04-00:43:10

Asch: Well, I mean, we were weird New Yorkers.

04-00:43:15

Lage: But you went to national conventions, and --

04-00:43:17

Asch: Yeah. But, I mean, they thought we were weird. They tolerated us, because we did these things --

04-00:43:25

Lage: They didn't object to the demonstrations --

04-00:43:27

Asch: Oh, no, no, no. They were very excited about that. And then they took it up, and NFB started what was called NAC tracking for many years, until the whole accrediting machinery kind of fell apart.

04-00:43:43

Lage: What kind of tracking?

04-00:43:45

Asch: They would go picketing the meetings of this National Accreditation Council every year.

04-00:43:52

Lage: Oh, I see. I see.

04-00:43:56

Asch: And if you were to—[telephone rings]

04-00:44:04

Lage: Okay. Now we're back on.

04-00:44:06

Asch: So, I think that in 1974, when the Human Rights Law was passed, the ACCD was being founded. Jernigan, on the floor of the NFB convention—I didn't go that year, because I didn't have enough vacation time to take from my job at that point, to go, but I was told—and I was very upset—that he described me as having kind of betrayed the organization by representing myself as part of a coalition, and I was very, very, very crushed. I felt really that they ought to be proud of the fact that we'd gotten this law passed, and it was a really good law, and I'd worked really hard on it, and felt that this was one of the most important achievements of my life, for sure.

And I still think—thirty-three years later—it's one of the things about which I'm the most proud, is having been involved in that effort. And I also think if I hadn't done the kind of organizing and setting up those choirs and orchestras in high school—I learned a lot of organizing techniques, and publicity, and all kinds of things from that, and some of the same desire to collaborate and work with people that got me to create a choir and orchestra and put on these concerts got me to like working with people, and running around and doing all this lobbying, and trying to mobilize people, and persuade them to do things.

And so, I felt that we had done this work—not just me, but we had done it, and instead of being proud of us, they were criticizing us, and I was really, really unhappy.

04-00:46:30

Lage: Did you respond to it?

04-00:46:32

Asch: Well, Pat left the organization. He never went to another NFB event. I didn't leave the organization. I was very unhappy, so I didn't go very much, but I never totally left. So then, the law got passed, and then I got asked if I wanted to take a job working on it, and this was a real crisis, because first of all, I had a job that I liked pretty well, with people I liked, and I had spent my whole life not wanting to be a full-time disability-type person, and now, they were offering me a job to be a disability rights person, but I didn't really want to be a disability rights person full time, but I did want to get the law implemented.

04-00:47:33

Lage: So this was with the --

04-00:47:35

Asch: State.

04-00:47:36

Lage: -- State Division of Human Rights?

04-00:47:37

Asch: Yeah. Right. They were also offering me a pretty big salary increase, so I went down and met with the person that I would work with, whose name was Lydia Clarke, and she was this really—she's no longer alive, I think. She was a really smart, very knowledgeable person, who had worked with the state for several years, knew the bureaucracy, had good values, was a really hard worker, and she was one of the reasons that I was persuaded to take the job. So then for the next three years before I went to graduate school, I worked for the state, for the first year and a half, doing work to implement the law itself—to try to train people throughout the state on how to think about the law, and what it meant, because they'd been doing race and sex discrimination, but they hadn't thought about disability discrimination, and they weren't necessarily going to be any better than the city commission had been.

04-00:48:59

Lage: I can see why you found this important, given your experiences with the city.

04-00:49:04

Asch: Right. But they also were better investigators. So, for the next year and a half, I went around, both being a spokesperson for the existence of the law, and reviewing other people's investigations to see—I mean, I had a great job. I reviewed other people's investigations to see if they had done a good job. It was a very responsible and interesting job. So I decided to take it, and I think

that was the right decision. And then—and this was both good and bad—they felt after a year and a half that they had learned how to do this investigating, and they weren't freaked out by disability discrimination, and so they said, "Why don't you just become a regular investigator, and investigate all kinds of cases?" And in a lot of ways, that was perfect. I believed in civil rights, I wanted to do all kinds of investigations, I thought I could do them—

04-00:50:20

Lage: You hadn't wanted to be put into a box.

04-00:50:22

Asch: I hadn't wanted to be put into a box. So, I was very excited. So that was great. There was only one problem. The person heading the unit that I got put in was just a very difficult person, and everybody knew she was a difficult person. And then her kind of authoritarianism and cruelty collided with some of my own work problems that I still had, in getting work done, and doing it quickly, and doing it efficiently, not being late, and not getting torn up by my own neurotic problems in my own relationships, and all the other kinds of work things that I had just as a human being. Her authoritarianism and cruelty collided with that, and I had a very difficult next year and a half, and I could never decide whether I was doing a good enough job, because she was a very, very, very mean person, and never said anything was good—whether it was or not. But the fact was, we had the law. It was being implemented. It was being implemented well. I had had a hand in getting it implemented. I was really happy.

04-00:52:01

Lage: You were feeling better about yourself, I would think.

04-00:52:04

Asch: Oh, yeah.

04-00:52:05

Lage: Than after college.

04-00:52:06

Asch: Yeah. Because I was doing something that I thought was meaningful. [telephone rings] I'm sorry.

04-00:52:17

Lage: We're back. The difficult position.

04-00:52:22

Asch: So, in 1976, the ACCD was looking for an executive director, and six of us applied. I wasn't sure I wanted the job, but I had been doing enough disability work that I wanted to think about it seriously. Anyway, I didn't get offered the job, and that was okay. I wasn't crushed by that, although I did find it quite amusing that at one point, we were each asked—the three finalists—what our salary requirements were, and we later compared notes, and the non-disabled man gave the highest salary, and the disabled man gave the next, and I gave

the third. Now, I was also the youngest, and had the fewest degrees, so in a lot of ways, that made sense, but it was kind of funny.

04-00:53:47

Lage: And who did they choose?

04-00:53:49

Asch: They picked Frank Bowe, and I think he was a very good choice. I wasn't sure that I wanted to move to Washington. I was still involved in this relationship, and I wasn't sure that I wanted to leave New York, and whatever. So I wasn't crushed that I wasn't picked. In 1976, the summer—yeah, I think it was the summer of '76—people were writing regulations to implement section 504, which of course hadn't been signed into law—I mean, it had been signed into law, but the regulations hadn't been implemented yet. I was involved with people. I was going down to Washington, meeting with people to write regulations, and it was very exciting. I mean, I liked --

04-00:54:54

Lage: Was this as an affiliate of ACCD? In what capacity were you doing this?

04-00:54:58

Asch: I don't know. Not really as an affiliate, just as a person. People knew me, and I'd gone to enough conferences, and I'd had the state experiences, working with the state law. And we had a big complaint history. I mean, in the first year and a half of implementing the State Division of Human Rights disability law, we had 600 complaints, which was way more than anybody ever expected we were going to get. They were similar enough to the kinds of things that were going to come up in the federal that I was really thrilled to be invited to do that. And by that time, Judy was out in—I remember going out to California in '76 to visit a woman who had been a high school friend of mine who was teaching at Berkeley. We were still very good friends then, and I had another friend out there, but in the course of those visits, I remember going to Ed Roberts' apartment, and seeing Judy and Ed Roberts, and somebody else—so, I was still quite in touch with disability advocacy, and whatever.

04-00:56:41

Lage: The movement.

04-00:56:42

Asch: Yeah. I mean, I still felt very much part of the movement. But it wasn't a big part of my social life. It wasn't a zero part of my social life. It just was— I never spent all of my social time with the movement. I was still doing music things, and other things, and so I saw this as an extension of the kind of antiwar work and civil rights work I'd always been interested in. I think something that made me a bit different in the way I approached the movement from, say, Judy—it's not that she didn't see those connections, between disability rights and sexism or racism or Vietnam, but she hadn't grown up in those movements. They hadn't forged her political identity, I don't think, in the

same way as they forged mine. So I turned a political identity that had been formed from living with my parents and reading about Clarence Darrow into disability. It wasn't the other way around. And I think that's why my embrace of disability as a cause and a passion has been—I don't know—slightly different, I think, from many people in the movement, for whom it's—it feels like it's the most important part of their lives.

04-00:58:48

Lage: I'm going to stop you right there, because it's --

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05-00:00:00

Asch: -- don't know. Even though I think there are people I like a lot, and respect, I think they see me as quite different from them.

05-00:00:15

Lage: In that you don't embrace the disability identity as certainly? Is that what you're saying?

05-00:00:21

Asch: Yeah.

05-00:00:24

Lage: Well, I would—I don't consider myself an expert on what they all feel, but I would agree with you. So, I think that's why I like the way the interview's going, because you really are showing how your—it's more than an opinion, but your identity has been shaped.

05-00:00:52

Asch: Yeah, I mean a lot of people view NFB, for example, as an organization that changes their lives, because it gives them—and I think for many people, this has been true—a sense for the first time of seeing blind people who are competent, seeing people who aren't ashamed of being blind, all that kind of thing. I don't think I was ashamed of being blind to start with, so I didn't—I mean, I remember hearing people at NFB talk about how they were ashamed of reading Braille on the bus, and I was like, "What are you talking about? I read all the time, everywhere. I wasn't ashamed of reading Braille. I wasn't ashamed of using a cane. The minute I got a cane, I started going places."

I think that meant that although I'm perfectly happy to know other people who are blind or disabled, and perfectly happy to get tips from them—if my computers break down, and they're blindness-related things, I call up people who know about adaptive technology. Or if I want to talk about—well, I moved back to New York, and the subway doors were a lot quieter than I thought they were. I'd never had trouble hearing the subway doors. The first thing I did was get a hearing test, to make sure that my hearing hadn't eroded,

and then I called other people who are blind, and said, "How are you dealing with the subway doors? They're really hard to hear." And they said, "Yes. It's true. They've gotten a lot harder to hear in the fifteen years that you haven't been in New York." And I consider people who are blind and disabled among my friends, and I want to talk to them about things, but that's true in the same way, I think, as I want to talk to other people who are Jewish about certain things, or other people who are bioethicists about certain things, or other people from Swarthmore. Swarthmore is the biggest identity thing in my life, in some ways—or, not the biggest, but it's one of them.

05-00:03:40

Lage: Really, now?

05-00:03:42

Asch: I'm sorry?

05-00:03:42

Lage: I'm surprised that you say that.

05-00:03:45

Asch: Oh, because I loved—I mean, I didn't like myself there, but I loved the place. I thought it was a great place. I thought it had the right values, I thought it stood for the right things. I thought the students were fabulous, I thought the professors were fabulous. So the fact that I didn't do well didn't mean that I didn't like the place. I'm surprised that you're surprised, given what I said about it earlier, because I don't think I expressed anything negative about *it*.

05-00:04:15

Lage: No, no, no, but just that it would be—you describe it as a very strong identification.

05-00:04:22

Asch: Oh, it is. I mean, people always tease me about its being such a strong identification, but when you go back to Swarthmore class reunions, usually there are a third of the class there. People love the place. They may hate it, too, or they may hate things about it, but they love the people they met there.

05-00:04:51

Lage: Do you think your attitude has anything to do with not having gone to a school for the blind? Is there a difference between people who come out of a school for the blind, and people who come out of situations such as yours? In their own attitude towards themselves?

05-00:05:07

Asch: I think so. I think that people who come out of schools for the blind are likely—not always, but likely—to have a much worse attitude about their sense of belonging in the world. I mean, I never questioned my right to be in the world.

05-00:05:27

Lage: So, rather than build a strong sense of self, at the school for the blind, they're—

05-00:05:31

Asch: No. Absolutely not. It's a totally segregated—it's everything that's wrong with Brown vs. Board of Education. It's one thing to associate with people by choice, it's another thing to be told that you have to, that they're "your kind," and you must associate with them, and you're not fit to be with other people.

05-00:05:52

Lage: Do you think your parents sensed that, when they moved to New Jersey?

05-00:05:56

Asch: Oh, yeah.

05-00:05:57

Lage: Or they just wanted to have you at home?

05-00:05:58

Asch: Well, it was all of those things. They didn't like the second classness of it. They wanted to have me at home. They didn't think it was going to help me become an independent person. Oh, yeah. I think absolutely. And I know very few people who are products of schools for the blind who I think haven't had very damaged lives as a result, no matter how professionally successful they've been. I think there has been—I mean, I don't know that many people, but all the people that I do know I would say have attitudes I don't want to have. And they're different. There's not one attitude, but either of overcompensation, or that they have to do more and prove themselves all the time because they weren't accepted in the first place, or they had very damaged relationships with their parents and their siblings, because they weren't there, or they didn't learn how to have ordinary friendships, just plain, ordinary friendships, because a lot of the peer relations, I think, were very screwed up. I mean, that's probably boarding school life. It could happen at any boarding school, but I think it has some of the worst aspects of boarding school and segregated school. It may build camaraderie, and it may build real close bonds, but it has those other things. I mean, everything has its price. Who knows what I didn't get, because I didn't go to a school for the blind. I don't think there's anything I didn't get that I want.

A lot of people now are sending their kids to Jewish day schools, who weren't sent to Jewish day schools themselves. They were in public schools. Well, if I had a kid, I wouldn't be sending my kid to a Jewish day school, even if I wanted them to grow up with a sense of being Jewish, because I really believe in public schools. I taught at a women's college. I don't really like women's colleges. I'm teaching at a Jewish university. I don't believe in—I mean, I'm teaching there for various reasons. There are good reasons to teach at both Wellesley and at Yeshiva University, but it's no accident that I didn't want to go to a Jewish university or a women's college. I think they're all—they have

missions, and they inculcate pride, and they inculcate solidarity, and they may do many good things, but I think you can have those things without being in that kind of cloistered, protected, sheltered atmosphere. And similarly, although I'm very glad that I've done all the things I've done with NFB, and ACCD, and other kinds of cross-disability things, and I assume I'll continue to do them for the rest of my life in one way or another, but I just don't think I could do them seven days a week, twenty-four hours a day. I'd miss too many other things and parts of myself.

05-00:11:02

Lage: Let me just ask you a couple things I wanted to ask you about the seventies. Did you get very involved in the deinstitutionalization issue and Willowbrook?

05-00:11:11

Asch: I mean, not directly. I mean, I think I knew people—Doug Biklen, and Bill Bronston, and other people who were doing that work were in this Policy in Action Conference on the Handicapped Coalition, and I completely supported it and agreed with it. I don't know if I went to more than one demonstration about it. I may have done that. I certainly— Yeah, I guess that's what I would say. I considered it part of my general sense of “movement,” so in the same way, whenever I'm on a bus in New York City and the back door opens and someone gets on the bus using a lift, there's a way in which I kind of smile. I'm happy. I'm glad that lift is there. I'm glad that person is getting on that bus. I feel a kind of—I do feel a kind of connection to the fight to get those buses lift-equipped. I don't want to be put in a wheelchair at an airport, but I want those lift-equipped buses.

05-00:12:46

Lage: And how about the 504 protests? Did you get involved in those?

05-00:12:50

Asch: Yes. There was a New York City demonstration, and I did go to it. I was working full time, and I couldn't take too much time off. I mean, I was working for the State Commission for Human Rights, and I couldn't do that as part of my job, and I didn't have vacation time to take off, but I did go at least one afternoon and evening, as part of the New York City demonstration. I did go to the White House Conference on Handicapped Individuals. It happened in May, right after the regulations had been signed, and actually helped stage a conversation between Judy Heumann and Kenneth Jernigan, which was pretty funny.

05-00:13:42

Lage: Oh, interesting. Tell me about that. What do you mean, "stage" a conversation?

05-00:13:46

Asch: Well, not stage. I mean, I was there when it happened.

05-00:13:51
Lage: Was this a formal conversation in front of a group --

05-00:13:53
Asch: No, no, no.

05-00:13:53
Lage: -- or just the two of them?

05-00:13:54
Asch: No, it was just a conversation at a dinner table, or something. I don't remember exactly how it happened, and I don't really remember anything much that got said, but it was great to see these two kind of iconoclastic people in their very different ways, with their very different styles be at the same place. And to know that I was—you know, respected enough, sort of. I mean, Jernigan was still mad at me for doing my cross-disability work, but respected enough by each of them that I think I helped persuade them to have the conversation.

05-00:14:49
Lage: Did they have a meeting of the minds?

05-00:14:51
Asch: Oh, I don't remember. I don't know if they said anything important enough to have a meeting of the minds, except that they thought the conference was a stupid conference—which it was. It was really a terrible conference. It was as paternalistically run as you could imagine.

05-00:15:04
Lage: Really?

05-00:15:05
Asch: Oh, yeah. It was just utterly dumb.

05-00:15:07
Lage: Now, who put it on?

05-00:15:09
Asch: I don't remember. I mean, it was the White House Conference on Handicapped Individuals, and it had these --

05-00:15:17
Lage: After 1977?

05-00:15:18
Asch: No, it was *in* 1977.

05-00:15:20
Lage: *In* 1977.

05-00:15:20

Asch:

It was the end of May of '77. And it was this conference that had been scheduled for a long time, and they didn't know that the regulations were going to get signed three weeks before, but of course everybody was really ecstatic, because the regulations had finally been signed, and Judy was a hero. I mean, she had done it. The San Francisco sit-in had done it, and I think there's—I forget. There was some protest about something, and I think I got quoted in the *Times* at the end of that conference, saying how stupid the conference had been. I don't remember. But I think there's some quote—I got interviewed by some reporter about how ridiculous the conference had been.

05-00:16:36

Lage:

Okay, I'm trying to—we have only about ten minutes.

05-00:16:38

Asch:

Okay.

05-00:16:38

Lage:

I was going to ask you to talk about feminism next, and the intersection in your own life between disability and feminism, but is that something—I know Denise McQuade was one of our interviewees, and she talks about consciousness-raising women's groups that took place at the Rusk Institute, within the disability movement. Was that something you were a part of?

05-00:17:15

Asch:

Uh-uh. Well, I mean, yes and no. In the seventies, I was in a women's group of people that I knew from work, and it was okay. I mean, it was an all right women's group, and I felt some commonalities with some of those women, and some not, and I felt—yeah, I guess that's what I would say. I mean, I didn't particularly think that disability played vastly into my experiences as a woman. I mean, I thought there was disability discrimination, and there was feminism, and they were not particularly—I mean, they were related, in that I had a disability and I was a woman, but I wasn't interested in—I mean, it was bad enough to be doing feminism and disability work. The idea of doing feminist disability work was just—you know, that was too much. All right. But when I was in graduate school—in '77, I started graduate school at Columbia in social psychology, and I also started a psychotherapy training program.

05-00:19:13

Lage:

In '77?

05-00:19:13

Asch:

Yeah. In September of '77. So I took a leave from my job at the State Division of Human Rights, and I went into these two different educational programs. Now, one of the dumbest things I ever did was try to do them both at once, but that's another matter. In the course of my experience at Columbia, I met Michelle Fine, who was a very powerful person who was interested in feminism, and we became friends, and about two years later—three years

later, I guess—she asked if I would write an article with her on double discrimination, because there was a call for papers of some journal, called the *Journal of Sociology and Social Welfare*, and they wanted to do a journal issue on the double discrimination of disabled women. And I said, "Well, I'll write an article with you, but I won't argue that there is double discrimination until we find out whether it's true. So if we want to do the research to see whether it's true, that would be really interesting, but I'm not convinced that it's true." And so that started us on the research, to reading the literature, and to meeting with women with disabilities, and putting together groups that had women with and without disabilities in some of the same groups, and talking about commonalities and dissimilarities in our experiences.

There was a great moment when Letty Cottin Pogrebin-- who had been one of the editors of *Ms.*—and Judy Heumann were on the same panel, and Letty Cottin Pogrebin was talking about thirty years of sexual harassment, and sexual objectification, and how all women experience that, and Judy said, "You've got to be kidding. You try living without any objectification for most of your life." And Letty Pogrebin was just totally floored. I mean, she didn't know what hit her. It was sort of like, "What do you mean?" And Judy said, "You're in a wheelchair, people don't see you as female. They just see this wheelchair, and you don't count. You're neutered." So I think for a lot of feminists, the idea that women with disabilities were *women* was hard to—it wasn't that feminists had any better view about disability than anybody else.

05-00:22:51

Lage:

But you're saying they failed to see women with disabilities as women, or as women who shared the same issues, or...

05-00:23:00

Asch:

Well, they didn't see how we either shared the same issues or didn't share the same issues. When a group of us put together one of these first National Conferences for Disabled Women and Girls in 1982, where we talked about some of these ideas, all these non-disabled women who were at the conference—you know, they didn't know whether to shake your hand if you were in a wheelchair, and if you had quadriplegia, should you come over and take somebody's hand, or not shake it, and they acted just as stupid and scared of people with disabilities as anybody else, because they'd never met people with disabilities, and they weren't used to seeing women with disabilities at feminist conferences. It was kind of like, "What are you doing here?"

I had gone to various pro-choice marches in the seventies, but I didn't think it—I mean, I wasn't going as a woman with a disability, I was going as a woman who was pro-choice, and I certainly knew from just that kind of funny example that the three of us who'd applied to the ACCD job, the non-disabled man asked for the highest salary, and the disabled man asked for the second, and I asked for the third, and I knew that a lot of that had to do with age and numbers of degrees, but it was possible that it had to do with some kind of

being accustomed to less money as a woman. I couldn't say that for sure, but who knew? And the data were that women with disabilities were paid less than men with disabilities or women without disabilities.

So the research showed that there was discrimination, and there was discrimination in people's attitudes towards women with disabilities, and I thought Michelle came up with a great title when she came up with the title for the first article that we wrote on the topic: "Disabled Women: Sexism Without the Pedestal." It was a fabulous title, and I thought that summed it up. I mean, there was discrimination, it was bad, as a national data issue, it was worse than women without disabilities, and it was worse than men with disabilities, and you were not pedestalized. You were patronized.

But I have to say, when I started going—I got asked to go to the National Conference on Women and the Law, and it was very clear I was going as a token. They needed a disabled woman. Well, I'd written an article on disabled women, and so then they brought me as a disabled woman, to be on—

05-00:26:37

Lage: Now, when was this?

05-00:26:38

Asch: Oh, this was '82, and '83, and '84, I think. One of my favorite moments at the National Conference on Women and the Law, which had hundreds and hundreds of women—lawyers, and judges, and all kinds of people doing law stuff, and they had caucuses. And they had caucuses for this, and they had caucuses for women of color, and then they had caucuses for lesbians of color, and they had caucuses for low-income Appalachian women, and then they had caucuses for low-income Appalachian women of color, and then... And I just thought—all I could think of was, "The greatest blind woman Jewish poet of the Confederacy."

05-00:27:24

Lage: That's what I was going to say it sounded like.

05-00:27:26

Asch: And at one point in the middle of this conference, I ran into somebody who was from Swarthmore, and I said, "Let's have a Swarthmore caucus!" But I just thought it was stupid. I thought, "Come on. By the time you get us into all these little boxes, there'll be nobody here!"

05-00:27:43

Lage: Oh, that's fascinating.

05-00:27:51

Asch: I had my doubts. I mean, it was fine to represent disability, and I thought it ought to be represented, but I just thought instead of coalition, you're making these teeny, teeny boxes, and I really didn't like it.

05-00:28:12
Lage: And were you the only woman with a disability, so you really couldn't have a caucus?

05-00:28:18
Asch: I didn't want a caucus! I wouldn't have had a caucus if I could have! I don't remember whether I was or not, but the last thing I needed was a disability caucus. I mean, I kept saying, "Look at all the things that I have in common with you. I'm white, I'm straight, I'm Jewish, I'm an academic. You're putting me here for my differences. What about all these similarities?"

05-00:28:50
Lage: It is 1:00, so we need to—we could hold this off until next time.

05-00:28:55
Asch: Well, just finish your question.

05-00:28:56
Lage: But I wondered—I noticed in the acknowledgements for your book on women with disabilities, here's what I wrote: you acknowledge people who've helped, parenthesis, (forced) you to think about what it means to live in this society as a woman who also has a disability, so I wondered if you'd shifted --

05-00:29:19
Asch: Well...

05-00:29:21
Lage: -- your perception, or analysis, as a result of all the work that led up to the book *Women with Disabilities*.

05-00:29:31
Asch: Well, I mean, I had this opportunity to do this work, so I did it. About fifteen years ago, I think it was Susan Sygall—do you know that name?

05-00:30:10
Lage: Yeah.

05-00:30:10
Asch: Okay. Susan Sygall came up to me one day at something or other, and said, "Well, how do you feel about being a Jewish disabled feminist?" And I said, "I don't really feel anything about it. I just am." And I said, "I don't like those labels. I'm not—I'm just..." Yes, I got forced to think about it in the sense that someone said, "Let's do this research." So, I did the research, and I found out from hundreds of studies that women with disabilities were more discriminated against than men with disabilities or than women without disabilities, but it's not as though I had some "ah-ha" moment, like, "I feel doubly discriminated against." I didn't *feel* doubly discriminated against. I felt occasionally discriminated against as a woman, and frequently discriminated against as a person with a disability, and --

05-00:31:28

Lage: It didn't help explain things that had happened in your life, it seems.

05-00:31:34

Asch: I don't think it had anything to do—well, what happened in my life?

05-00:31:37

Lage: I don't know.

05-00:31:38

Asch: I'd fucked up at Swarthmore, and I'd had a lot of discrimination in jobs. I'd fucked up at Swarthmore *quite* on my own. I had screwed up at Swarthmore just the way Ellen, and Judy, and Valentine had screwed up at Swarthmore, and just the way that various men I knew had—Allan Trosklin (spelling?)—had screwed up at Swarthmore, and they weren't disabled, and Allan was not female, and I mean the discrimination I had had virtually exclusively been about being disabled. I mean, professionally. Perhaps occasionally about being female, but not very much. Until the eighties—I mean, I was in romantic relationships until the early eighties, so I hadn't felt particular social rejection at a deep level as a woman with a disability, or as anything else. I mean, I'd had relationships that worked and relationships that didn't, but again, I felt that the relationships that worked worked for whatever reasons, and the relationships that didn't work didn't work for whatever reasons, and I didn't think that being disabled had much to do with why they worked or why they didn't. I don't know how being a woman with a disability explains very much of my professional life, one way or the other. It may explain some things about parts of my social life. We can get to that.

05-00:34:14

Lage: Do you think it explains societal problems? I mean, someone like Harilyn Rousso, I think, would put it as kind of a central concern, a social concern: treatment of women and girls, and self image.

05-00:34:29

Asch: Well, I mean, she would, but that's Harilyn.

05-00:34:32

Lage: Yeah, that's what I mean. Aside from personal life, would you --

05-00:34:38

Asch: Well, I can't experientially say that that's a problem, because it wasn't for me, but I'm not—if you have hundreds of thousands of people telling you it's a problem, it's a problem. I don't know what to say, Ann. I mean, Harilyn thinks that I'm living in some state of denial. Well, I can say things about my social life that have to do with disability. I can say things about my professional life that have to do with disability. I don't think I have been discriminated against in a massive way for being a woman with a disability, or for being a woman. I think my self image is a complicated thing. I care a lot about appearance in the way that women, probably more than men, are taught to care about appearance: Do I have the right blouse? Are these earrings good earrings? I

care about those things. I care about presenting a good image, but I have a professional job and a social life to maintain where image—not image, but where presentation matter. I'm not sure what to say.

05-00:36:42

Lage:

Well, I think maybe we've said it—you've said it—on that topic. I don't know that we need to get you to say something other than what you've experienced, and believe.

05-00:36:55

Asch:

The thing is, Marsha Saxton and Harilyn, and lots of other people would say that being a woman with a disability is different from being a woman without a disability. Well, that's probably true, in certain ways that I've already alluded to. Women without disability probably are more sexually objectified and approached than women with visible disabilities. I had a sexual life during my teens, twenties, parts of my thirties, up till my forties. I haven't had a sexual life since then. I don't like that. I can't answer why that's true. Does disability play into that? Probably, in some ways. Am I looked past? Probably. I can't answer that, because if they're looking past me, they're looking past me. Do I get told horrible, outrageous, disgusting things about how I'm not partner material? Yes, sure. By dating services, and by therapists, and by ostensible friends. Has it caused the men who were in my life to reject me? I can't answer that. I don't think so. Has it prevented men from coming into my life? Does it have to do with being a woman with disability? There are plenty of happily paired women with disabilities. So. . .

05-00:39:52

Lage:

And unpaired women without disabilities.

05-00:39:54

Asch:

And unpaired women without disabilities. So I can't answer that question. I wish I knew the answer. Everybody assumes—or, by everybody, I mean therapists, and professionals, and friends assume that disability is a lot of the story. Well, maybe it is, maybe it isn't. I can't--

05-00:40:33

Lage:

It's an unanswerable question.

05-00:40:36

Asch:

I had a therapist who said, "If you weren't blind, you'd be married." Well, maybe, but I don't really know on what basis he said that. I mean, he may have said that because he didn't think I had the kind of psychological problems that some people who are unpaired have. Do people reject me when I approach them? Yes. But do they reject me more than other people are rejected? I can't answer that. Sometimes I suspect yes, but I don't know. I mean, I haven't been approached in a romantic way in a long time.

05-00:41:32

Lage:

We haven't even mentioned the word ageism.

05-00:41:37

Asch: Yeah, well, that's another problem. But I mean the people that I'm talking about are approaching people my—our—age. I mean, I'm not talking about people who want to go out with twenty-year-olds. I don't have an answer to that. I just don't know.

05-00:42:21

Lage: Well, you know, if you feel uncomfortable when we finish this and you get to see the results, we can seal it. You don't have to --

05-00:42:34

Asch: Well, I mean I guess I think you want a personal history, you know, this is a piece of it. It's quite out of order, but it's—I don't know. Sorry, Ann. I don't quite know where to put this.

05-00:43:32

Lage: It may not have been an issue during the period we were talking about, when you first started doing the work with Michelle Fine, but maybe since then. At any rate, I think we should stop now, because it's 1:15.

05-00:43:53

Asch: All right. Do you feel—I mean, there's a little more to say about women with disabilities, slash then getting into bioethics—I mean, then there's a lot to say about bioethics, and such.

05-00:44:08

Lage: Right. And certainly there's some crossover there, in terms of feminism, abortion rights, all the issues that intertwine.

05-00:44:19

Asch: Yeah, but --

05-00:44:20

Lage: It's different from these personal issues.

05-00:44:22

Asch: Yeah, but people think about this feminism abortion stuff as women with disabilities and bioethics, but it's actually not.

05-00:44:30

Lage: But it's something to talk about, why it is, or why it isn't.

05-00:44:34

Asch: Yeah. Am I right? That's your last kind of big topic?

05-00:44:43

Lage: Right. Should I turn off, now? Are we --

05-00:44:48

Asch: Yeah.

End Audio File 5 asch_adrienne5_06-20-07.mp3

[End of Interview 2]

Interview #3: June 21, 2007

Begin Audio File 6 asch_adrienne6_06-21-07.mp3

06-00:00:06

Lage: Okay. Today is June 21, 2007, and we are at the third session with Adrienne Asch. I am Ann Lage, and this is tape six. We were just reviewing last time. We finished with a discussion basically about identity, not just disability identity, but categories, and your dislike for boxes, which I thought was very interesting, and also about women and disabilities, and from there—the last thing I thought of as we were winding that up was connecting that to your scholarship, either now or later, as it comes along. I think we should connect some of those personal values and points of view and concerns with your scholarship, if there is a connection.

06-00:01:10

Asch: Yeah, well, there is. All right. Well, why don't I try to more quickly go through, just to explain how some things happened.

06-00:01:20

Lage: Okay.

06-00:01:21

Asch: And part of what's complicated is that for many years, I was doing more than one thing at a time. I was getting a therapy certificate, I was in graduate school getting the PhD in social psychology, I was employed by the New York State Division for Human Rights, doing civil rights investigations. I was still doing both academically and sort of as a volunteer certain amounts of disability rights-related work, and so all of those things were going on. This is, say, between 1977 and 1984 that I'm talking about. And some of that wound up involving scholarship on women with disabilities, because, as I say, Michelle proposed that we work together on the article that became "Disabled Women: Sexism Without the Pedestal," that was published in a journal in 1981, and then published as one of a number of pieces in a book, edited by Mary Jo Deegan and Nancy Brooks, that came out in 1985.³

By the time that came out, Michelle and I had decided to edit our own anthology on women with disabilities, and also to edit a journal of social issues on disability and discrimination, and the disability rights movement. And so I was launched on those two academic projects while I was a graduate student, and eventually wrote some articles that both helped me with graduate

³ Deegan and Brooks, ed., *Women and Disability: the Double Handicap* (New Brunswick: Transaction Books, 1985).

school and became part of the literature. I wrote an article on the disability rights movement for a book that came out in 1985. I wrote some articles that appeared in the *American Psychologist* in 1984, and started going to academic conferences, sometimes talking about disability and discrimination—whatever. I mean, just a variety of things. Harilyn Rousso and I and some other people who were all in training in psychotherapy in New York got together and created a conference on mental health practitioners with disabilities, and that resulted in another paper on the way that disability was treated by the psychoanalytic and psychotherapy professions, both in terms of people who were clients of psychotherapists and people who wanted to be psychotherapists.

06-00:04:47

Lage:

Did that grow out of your personal experience?

06-00:04:49

Asch:

Well, yeah. I was in training to be a psychotherapist, and I'd had a great deal of discrimination in the entrance into psychotherapy training programs, as had Harilyn, and as had some other people, and we were in training, or we were already established clinicians, but we'd had experiences as clinicians with disabilities who were treated badly by the profession. So there were always certain—when I went to graduate school, one of the things I was particularly interested in was studying discrimination. What I was really interested in was why some men were feminists, and why some whites got active in the civil rights movement. I mean, I was interested in—as I put it at the time—why some people got involved in other people's causes. Why did some people understand that so-called "other people's causes" were their causes, too? Now, I never actually wound up doing too much in that, but that was an impetus for my going into social psychology. It's still an interest. I might study it yet. In the course of all of this *mélange* of activity that was—there got to be less and less separation—if there ever had been—between work, and volunteer work, and political work, and professional work. All of it all sort of melded.

06-00:06:39

Lage:

All your various parts.

06-00:06:40

Asch:

Right.

06-00:06:41

Lage:

They didn't collide?

06-00:06:43

Asch:

No. They didn't collide. I don't think they ever collided. Other people may think they've collided—a lot of people talk about how the women and disability issues collide, but they don't.

06-00:07:02

Lage:

Well, I'm thinking also of things like scholarship and advocacy --

06-00:07:05

Asch:

Well, they don't collide, either, because I'm making points that I think are important policy and social issue points as a scholar. I'm studying problems. They would collide if I thought that you should suppress ideas in order to be a good advocate, but I don't think that. In fact, I think you can't be a good advocate by suppressing ideas, so for example—well, this comes up.

This is a very interesting kind of question in some of the discussions about race and genetics, for example. This is skipping ahead, but just to give you a sense of what I mean. Some people want to say, "Well, the people who want to study the genetics of intelligence have racial ends in mind." And they may. Some people may want to prove that Asians are smarter than whites, or that whites are smarter than somebody else, or whatever. They may want to prove that. We don't know whether they will prove it or not. I think it's unlikely, because I think lots of things are social—how do we determine what intelligence is, et cetera, et cetera. But even if there were a way to prove that, oh, say, print reading was always faster than the fastest Braille reading or speech reading—let's say that's true. I don't know that it's true. People always assume that as a person who reads with speech or Braille, I have to be slower than the average college educated print reader. Well, maybe I am. I don't know. I've never done a test. But let's say we did a very carefully well worked out study, and no reader using speech or Braille was as fast as the average highly educated print reader. Well, I don't think you accomplish anything by suppressing that information if it turns out to be true. How you interpret that information is what's important. What implications it has for education, or policy, or whatever, is important. But I don't see why advocacy and scholarship—I mean, they ought to be in the service of one another.

06-00:10:11

Lage:

The example I thought you were going to bring up—maybe you don't consider it as an example—but apparently there was a controversy over your debating Peter Singer.

06-00:10:21

Asch:

Well, I mean --

06-00:10:22

Lage:

At the Society for Disability Studies, was it?

06-00:10:25

Asch:

No, there wasn't—I don't think there was a controversy. Some people thought I shouldn't have done it, but lots of people thought I should do it. I mean, I don't think it was a monolithic thing. Maybe some people thought I shouldn't do it --

06-00:10:39

Lage:

But there was that kind of discussion—I'm thinking about—whether those ideas should be brought forth in that way.

06-00:10:45

Asch:

No one ever came to me and said, "You shouldn't debate Peter Singer." If they had, I would have said, "Well, I'm sorry. I think that that's not a good way to solve the problem. I think Peter Singer's out there saying what he says, and it won't accomplish anything not to debate him." If we want to show that his ideas are wrong, you have to challenge them. You can't just say, "They're wrong and I won't discuss them." I mean, I'm pretty hard line civil libertarian about this.

06-00:11:25

Lage:

Right.

06-00:11:27

Asch:

I think the only way to deal with ideas is with other ideas. I don't believe in suppressing ideas. I mean, actually, someone at Princeton when I was debating Peter Singer, someone in the audience asked me whether I thought Princeton should have hired him, and I said, "On grounds of academic freedom, of course Princeton should have hired him. On grounds of scholarship, I think his scholarship on certain points is very poor, and they shouldn't have hired him." But on grounds of academic freedom? Sure. Unless you can show that his scholarship is bad—which I think you can, on some things, anyway. So I don't see scholarship and advocacy as colliding, and—
[telephone rings]

06-00:12:19

Lage:

I didn't want to divert you. I think you've made the point. You were talking about how the various parts of your life fit together, and you were going to go somewhere from there, and I think I led you off in a different direction with the Peter Singer question.

06-00:12:32

Asch:

Well, no, that's fine. Actually, one thing I wanted to say about this particular article I wrote on the disability rights movement: a lot of people within the disability rights movement and the independent living movement—and I have felt this for a very, very long time—when it's convenient politically, we want to say that we speak as a movement for fifty-four million people with disabilities in the United States, and yet there are many people in the movement who want to say that the only people who count as people with disabilities have visible disabilities, have physical disabilities, and have disabilities from early childhood, and don't want to count as real disabled people [*Adrienne--complete thought here?*]
—Phyllis Rubinfeld was someone who felt this very strongly. I don't think that's how DREDF feels, I don't think that's how Judy Heumann feels, and I don't think that's good for the movement. I think the movement has to be as broad as the Rehabilitation Act, and the Americans with Disabilities Act are—or were imagined as—in their definition of who counts.

Similarly, I think that even though the National Federation of the Blind has eschewed cross-disability work, and even though I think that's a mistake, in ways that I tried to say yesterday, I think NFB doesn't get its due in the Berkeley world and in the independent living world for being a genuine disability rights group. I mean, it's not countercultural. It hasn't learned a lot of the lessons of the sixties. It can be stuffy, or formal. It's getting better, by the way, but it can be [fire alarm sounds]—Oh, no.

06-00:15:01

Lage: Is this a fire alarm?

06-00:15:02

Asch: It's a fire drill. [tape interruption]

06-00:15:04

Lage: Oh, my God. That was a very brief interruption.

06-00:15:09

Asch: Yeah, what I was saying is that I don't think NFB gets its due as a serious, committed organization, committed to the goals of disability rights. I think because there have been debates within the blind community about whether blind people need audible traffic signals, or how much adaptation we need to live in the existing world, and ACB has been on the side of more adaptation, and NFB has been on the side of less adaptation—

06-00:15:47

Lage: And why is that? I mean, what's the thinking there?

06-00:15:50

Asch: Well, I think the thinking—and I tend to subscribe to NFB thinking on that, although I actually don't much care about this one. The fact is, what NFB wants to say is, "Look. Architectural adaptations and accessibility are important for some portions of the disabled population, but blind people can get around without audible traffic lights by listening to the traffic." Now, that's not going to be true if we actually have more and more quiet cars.

06-00:16:24

Lage: More Priuses.

06-00:16:25

Asch: If we have more Priuses—and everybody in NFB knows that. So, we're now—NFB is working on that problem. Similarly, when Windows came along—I mean, DOS and the computer environments of the eighties and early nineties were very user-friendly for text-based screen readers and Braille displays. Windows was not a very accessible—you know, graphic user interfaces complicate your lives, and NFB worked to adapt—I mean, I think NFB's view is adapt what has to be adapted and adapt as little as possible, because most of the time you can function without adaptation. And I don't think that's wrong. I don't think NFB is stupid about it. I think ACB, for whatever reason, and I don't know the reason, has been more on the side of

things need to be adapted, and I think one of the downsides of that view is that the more you claim that your needs are special and different from other people's ways of doing things in the world, the more you can have employers and employment agencies saying, "Well, we can't serve you or deal with you, because you need all these special things that we don't have." So NFB, I think, has said, "Let us deal with our own accommodations, make our own arrangements. Don't tell us what we need. Let us tell you what we need, and when we need it, so that you'll let us get in the door." And I tend to subscribe to that view. It's not that I don't want help—and that can be all kinds of help—but I want to decide when I need help, whether it's emotional help, or physical help, or any kind of help.

06-00:18:57

Lage: Does this fit with what you said about your attitude about services for college students?

06-00:19:05

Asch: Yeah. I think that many times disabled student offices become police and set up extra requirements that no nondisabled student would tolerate: "You have to live in this dorm, not that dorm. Don't take this course, it's too hard. It has too many requirements."

06-00:19:30

Lage: You've seen that in action, it sounds like.

06-00:19:32

Asch: Oh, yeah. Oh, yeah. Well, not to me, but yes. Talk to lots of blind students within the NFB Student Division, and they'll tell you horror stories.

06-00:19:43

Lage: Do you think that's true of students with other disabilities?

06-00:19:45

Asch: I don't know. I don't see why not.

06-00:19:48

Lage: I just thought you might have had experience as a professor with --

06-00:19:51

Asch: Well, actually, when I was teaching at Barnard—well, to some extent, yes. This was interesting. The first teaching I ever did was a course in 1982 at Barnard called, "The Disabled Person in American Society," and it's one of the first disabilities studies courses probably ever that existed. Somebody asked me to design it and teach it, and it was really fun, but the disabled student office at Barnard—as a matter of fact, I did have some students with disabilities in the class—it was a small class. Now, I wasn't the greatest teacher, but one of the students came to me and said that she wanted to—she had a manual dexterity disability, and she wanted instead of writing a paper to do an oral in class, or interview kind of exam. She wanted to come to my office and do the exam.

06-00:20:51

Lage: Orally.

06-00:20:52

Asch: And I said no. I said, "That's not the equivalent of an organized paper." I said, "Let's figure out other ways." She said, "Well, I've never written a paper." And I said, "Well, you're going to do it now." I said, "You can dictate your answers into a tape recorder. You can dictate your answers to somebody else. You can type your paper. You can have an extension on the due date if you want, but you have to present me pages or tapes of organized answers. We can't have a conversation. That's not what I want. I want to give you a set of essay questions, and have you formulate your answers." Well, the disabled student office tried to talk me out of it, and I said, "Absolutely not."

06-00:21:47

Lage: That's very ironic, really.

06-00:21:50

Asch: And this student, who was a junior, and had taken a lot of other non-essay kinds of courses, then she did it—she did these papers that way, and got a B- or whatever, and then she complained about how she should have gotten a higher grade, because she'd worked so hard and she had never done this before, and I said, "No, you get the grade that your work shows. It doesn't mean that you didn't make a good effort, or that I don't appreciate that this is new for you, but this is the grade that this work earned. It doesn't mean you're a bad person, or that you won't do better on the next paper, but this is the quality of work that you produced." And I found it utterly outrageous that an office for disabled students would try to tell me how to run my course and teach my students. If I had refused—if I had made no accommodation of any sort, that would be one thing. I think I would have been in violation of 504, but I think I was absolutely within my rights, and I think I had thought about what accommodations were appropriate to meet the objectives that I wanted the assignment to fulfill.

06-00:23:33

Lage: I'm trying to lead us back to where this started, which was the NFB and your article on the disability rights and independent living movements.

06-00:23:43

Asch: Oh, well, I wrote about the disability rights and independent living movement for a book, and I talked about the importance of NFB as an example of a single-disability group.

06-00:23:54

Lage: I see. And did some people react to that?

06-00:23:59

Asch: No. I don't even think anybody knows about that article, but lots of people don't think of NFB as a genuine disability rights organization, and I think that's too bad. That's all. But I appreciate and I hope it's still true that people in

DREDF [Disability Rights Education and Defense Fund], and WID [World Institute on Disability], and CIL [Center for Independent Living] out in Berkeley, and other people from within the disability rights movement more broadly defined see me as a legitimate disability rights activist, even though I have been a member of NFB, and I do a certain amount of NFB work.

06-00:24:38

Lage: Do you think very many people in the movement are aware of tenBroek and his writings, and his --

06-00:24:46

Asch: Much too few. Nobody appreciates the power of tenBroek, or the importance of his article, "The Right to Live in the World."

06-00:25:00

Lage: I keep trying to look for connections between tenBroek and the Berkeley student group --

06-00:25:05

Asch: Well, there really aren't any.

06-00:25:06

Lage: -- I don't think they took classes from him, although --

06-00:25:11

Asch: Well, I mean he died in '67 --

06-00:25:14

Lage: Was it '69?

06-00:25:14

Asch: -- or '68. No—I think he stopped teaching in '68.

06-00:25:17

Lage: But he was actually ill for a while. [died in 1968.]

06-00:25:19

Asch: Yeah, so I think he stopped teaching—

06-00:25:21

Lage: But Ed Roberts was there in '62.

06-00:25:25

Asch: I see.

06-00:25:26

Lage: And he did graduate work in political science.

06-00:25:30

Asch: Well, it's too bad if he didn't. It's really too bad if he didn't. I would hope that tenBroek would have been very, very supportive. There's a wonderful essay that Lesley Frances and Anita Silvers wrote as the introduction to their book

on the Americans with Disabilities Act⁴, which talks very appreciatively about the work of Jacobus tenBroek, and I would love it if people knew about that, and actually, when the Berkeley conference—I think it was in 2000, when I came out and did that talk about tenBroek. It really made me happy to do that. I was really thrilled that people wanted me to do that talk, because I think he's a very important and impressive person, who deserves real homage in the world of disability rights.

06-00:26:37

Lage: Yeah. I do, too. That talk is on the Internet, by the way.

06-00:26:41

Asch: Oh, is it?

06-00:26:41

Lage: Yeah. Most of the talks at that conference, we have up on our site.⁵ So, hopefully, people are reading it.

06-00:26:50

Asch: Anyway. Okay. So, I'm still somewhere between '77 and '85.

06-00:26:56

Lage: Right, and we're --

06-00:26:57

Asch: Okay. Let me go back to how I got to—okay. In 1982, at this first National Conference on Disabled Women and Girls, Michelle and I wrote and distributed a piece called, "The Question of Disability: No Easy Answers for the Women's Movement," which was a very short piece, and what it was about was this whole topic of prenatal diagnosis and selective abortion.

06-00:27:35

Lage: Way back then in '82, '83?

06-00:27:38

Asch: Yeah. It was written and published in '82. And the article said, "You can be pro-choice and support abortion rights for women, and you can also support rights for people with disabilities, and those two things can and should go together, and they won't go together if people use a fetal disability as an automatic reason for a woman having an abortion, if women don't know enough about the life of people with these disabilities to make an informed

⁴ Francis and Silvers, ed., *Americans with Disabilities: Exploring Implications of the Law for Individuals and Institutions* (New York: Routledge, 2000).

⁵ <http://bancroft.berkeley.edu/collections/drilm/resources/symposium.html>.

decision." We tried to submit that to—[fire alarm sounds] I think we can ignore it.

06-00:28:31

Lage: Okay.

06-00:28:32

Asch: We submitted that to a feminist journal—a radical feminist journal—called *Off Our Backs*. They refused to publish it, claiming that we were guilt-tripping their readers, and so we submitted it to the *Reproductive Rights National Newsletter*, and this was a very controversial article. I had no idea just how controversial it was going to be, and it has affected a lot of my professional life—that and subsequent articles. So, arguing that you can be pro-choice and abort any fetus you wish, but that women and medical professional should think very carefully about what it means to say that you want a child, but you don't want *this* child, because of a characteristic that this child has—that that's a different statement from you don't want a child at this time. Now, I don't think that's so hard to grasp. I don't think it compromises women's rights to abortion. I don't think it compromises the rights of people with disabilities to exist. I'm simply saying, "Make a careful, informed decision. Get the information you need about life with disability. Genetic counselors and doctors should give it to you before you decide, 'I could never raise a child with Down's Syndrome, or spina bifida, or deafness, or muscular dystrophy, or whatever it is you can diagnose.'" But similarly, I've said—and this is where I depart from some people within disability rights—if I don't think that parents should select against a child based on a characteristic of spina bifida, I don't think people should try deliberately to have a child with a characteristic of spina bifida or deafness. I think that that's making the same kind of mistake as trying not to have a child.

06-00:30:51

Lage: Are there those who hold those two things together?

06-00:30:55

Asch: Yes. Yes.

06-00:30:56

Lage: At the same time?

06-00:30:57

Asch: Yes. That selecting for a characteristic is fine, but selecting against it is discrimination. I think that that's a mistake. I think people should be able to select *if they want*. I would prefer that they not. I think they shouldn't select. I think it would be morally better if they didn't select. I think after they get the kind of information they need, they should be able to select. Okay. So, this article was written, and feminists found it very threatening, I think.

06-00:31:42

Lage: So you're getting it from both sides, in a way?

06-00:31:45

Asch:

Well, I haven't gotten very much flak from people with disabilities. Mostly people appreciate that I've taken on this issue, but I think there are some who don't agree with my position. In any event, in 1982, I wrote this article. Then in 1982, the Baby Doe case in Indiana happened: an infant with Down syndrome was not fed, because there was a surgical intervention needed—sorry. The infant needed surgery to close an opening in the esophagus, and the physicians advised the parents not to give the infant the surgery, because the infant had underlying Down syndrome that wouldn't be cured. That became known as Baby Doe. Eventually, the Reagan Administration wrote what were known as the Baby Doe rules, saying that this was discrimination based on a disability. Because the Reagan Administration was anti-abortion, a lot of feminists, and civil libertarians, and leftists of all stripes—you know, were so angry at the Reagan Administration's anti-abortion stance, they felt that they weren't really interested in disabled newborns, they were just trying to get back at parents.

06-00:33:23

Lage:

And choice.

06-00:33:25

Asch:

And choice. And I wrote—along with Michelle—articles that said, "No, we don't think that's right. An infant is not a fetus, and a parent doesn't have the right to kill an infant—or let an infant die—because of a disability. Once an infant is born, the woman or couple don't have to raise that child if they don't want to, but they shouldn't have the right to kill it, if the infant will benefit from medical treatment." So that put me at odds with all of my left-wing political friends, and that was very depressing, but --

06-00:34:18

Lage:

When you say, "at odds," were they actively condemning of it?

06-00:34:25

Asch:

Well, they thought I was completely wrong. They would talk about how awful the Reagan Administration was on all the other things they were awful in, and say, "And look, they're telling parents they have to raise these children with spina bifida and Down Syndrome who otherwise would die, and it would be so much better for them." And I'd say, "Well, I don't look at it that way." And in the course of putting together this course on the disabled person in American society that I taught at Barnard, I got hold of a book on bioethics to look at some of the philosophical frameworks that it used, and I saw a lot of article in bioethics that treated some of these topics on disability, and treated them very poorly, I thought. So in 1983, the Elizabeth Bouvia case happened in California.

06-00:35:38

Lage:

Give a little framework for that.

06-00:35:39

Asch:

Elizabeth Bouvia—and it's not pronounced "Bouvier;" it's pronounced Bouvia: B-O-U-V-I-A—who was a woman with cerebral palsy, who'd had cerebral palsy, obviously, all her life, was twenty-six. She went to Riverside County Hospital asking for them to keep her comfortable while she decided to starve herself to death. She maintained that she was very depressed, that the pain of her arthritis was getting worse, and that she no longer wanted to live, and she was declared competent psychologically and mentally, and the ACLU went to court to support her—quote—"right to die." Carol Gill, and Paul Longmore, and Harlan Hahn, and some other people got involved in this case—I thought very appropriately. I don't remember exactly how I heard about it.

I don't remember who called me up, but I was completely supportive of their involvement. I said I thought that it was completely right. And they said, "Look. If this were a nondisabled person who did this because of the various stresses in her life--" Her mother had died, and her brother had cancer, and her father didn't want her to stay in his house anymore, and she'd been thrown out of school, and her marriage had ended, and she'd had a miscarriage. She had all these things that would have made anybody depressed, and if she had been non-disabled, her psychiatrists would have given her treatment, instead of saying, "Well, yes, we can understand why you want to die. We'll help you."

The argument was made that everybody was letting her disability be the reason to let her die, rather than treating the profound depression she was in, because of a whole host of life circumstances, some of which had been discrimination, and some of which were a bad set of personal circumstances that anybody could have been thrown by. And that made it different from a sort of typical right-to-die case—not that there is such a thing as a typical right-to-die case—but this woman was not dying. She didn't have to die. She could have lived for years. And, in fact, eventually she decided to leave the hospital, and not to starve herself to death, and although I don't know where she is and what she's doing, as far as we do know, she's still alive.

There then came some more of these cases: the David Rivlin case, the Larry McAfee case in the next several years. As a result of this set of cases, I was getting more and more interested in bioethics as a topic.

06-00:38:55

Lage:

And you're still in graduate school here.

06-00:38:57

Asch:

I'm still in graduate school, I'm still doing psychotherapy, I'm still working for the State Division of Human Rights. But I got a call about going to a bioethics meeting, and went to it. Someone just happened to think I might want to go, and I went to this meeting, and then I went and introduced myself to people who were speaking at the meeting, and they said, "Well, do you want to get involved with the newborns project at the Hastings Center?" And I said,

"Sure." And they said, "Well, call up the Hastings Center and talk to Tom Murray. He's the co-chair of the project. And explain that I sent you, and maybe he'll let you come." So, I did. I called Tom Murray, and he said I could come.

And so in May of 1984, I went to my first bioethics meeting at the Hastings Center, and it transformed my life, really, ultimately. I didn't know that at the time, but I realized that these were the most important conversations I'd engaged in in years. They were really, really interesting. They were really complicated. They were really smart people—doctors, and nurses, and philosophers, and lawyers, and psychologists, and sociologists, and anthropologists. So I started going to more and more bioethics meetings at the Hastings Center as not entirely an outsider, because—I mean, there were insiders. I was younger than many people. I was in my mid to late thirties. I didn't have a PhD, which lots of people did, but they took me seriously, at least some of them did, and I learned how to hold my own. I didn't know what the hell I was doing when I first started going. I hadn't read any of the things that lots of people had read, but I started getting the Hastings Center report, and started to read it every month. And then I started going to more and more bioethics meetings, and the more I went, the more people invited me to go to more things, and so while I was still doing all of this other collection of things, I added bioethics to the set of things I was going to do.

06-00:41:26

Lage:

Was bioethics itself in sort of an infancy as a field?

06-00:41:33

Asch:

Well, it was about fifteen years old. The Hastings Center had been started in 1969. There was one major program at Georgetown University, where you could study with several people who were writing about bioethics. Eventually, people at the Hastings Center started bioethics graduate programs, first at the University of Minnesota, then at Case Western Reserve University, and at Galveston, the University of Texas medical branch. There were bioethicists at Montefiore Hospital that I met, and Albert Einstein College of Medicine. There were people at the University of Wisconsin, but there weren't *that* many.

06-00:42:31

Lage:

And it was a diverse group. From medicine to anthropology --

06-00:42:34

Asch:

Medicine, anthropology, and nursing, and philosophy, and law. And so in 1987, I still hadn't finished graduate school. I was still writing—by then I was working on all these articles that people were asking me to write, which wasn't getting my dissertation done, but was getting me to learn how to be a scholar. And some of them were this book on women with disabilities, and some of them were on reproductive technologies. Anyway, in 1987, I was invited to join the staff of the New Jersey Bioethics Commission. Its formal

name is the New Jersey Commission on Legal and Ethical Problems in the Delivery of Healthcare, and it had a five-year life. It was a very small organization.

06-00:43:37

Lage: Adrienne, I'm going to stop you for one second and --

06-00:43:41

Asch: This commission was started to look at two big issues within New Jersey. New Jersey had had two of the big bioethics cases in its state courts, the one having to do with Karen Ann Quinlan, and whether her parents could remove a respirator that was keeping her alive, and the Baby M case on surrogate motherhood. I was invited to join the staff because people had known me through my work at the Hastings Center, and so for three years, that became my full time job.

06-00:44:44

Lage: So, this was a paid position, not a --

06-00:44:46

Asch: This was a paid position. It was a very exciting position. I worked really on two big projects: surrogate motherhood and reproductive technologies generally, and advanced directives for healthcare.

06-00:45:18

Lage: And you were developing policy?

06-00:45:20

Asch: Well, all of us. It was a staff of six or seven people. We were writing recommendations for the legislature and for the governor, and so we were staff to a policy-making commission of 12 individuals, and so we would prepare working papers that they would then discuss at meetings we would convene. So, it was a research and policy job, and it was just incredibly exciting. It was also very demanding. We worked long hours. Three of us moved to—well, actually, I guess four of us—moved to Princeton to take the job. We worked ten hours a day five days a week, sometimes more. We practically never saw anybody but one another, and so it also had sort of the advantages and disadvantages of a family. We were at times a very functional and at times a very dysfunctional little group.

06-00:46:34

Lage: What were the backgrounds of the other people?

06-00:34:38

Asch: Three were lawyers, one was a philosopher—I mean, one was a lawyer-philosopher, two were lawyers, one was a policy analyst, and one was a very high-level administrative assistant—sort of executive assistant—and then me. At the time we started, I was forty-one, Ann was thirty, Rob was thirty, Alan was forty or thirty-seven—we were all between thirty and forty-five. We had in many ways a very good time. We worked really hard. At times, we didn't

get along for complicated reasons. Anyway, the commission—we produced some documents, we did some good work, we had our problems, but it was a fabulous experience in many ways for me. I really learned a hell of a lot.

06-00:48:11

Lage: Did the commission take up your recommendations?

06-00:48:15

Asch: Again, they weren't just mine --

06-00:48:17

Lage: Yeah, I mean the group's.

06-00:48:18

Asch: Oh, yeah. Well, that's what we did. Did they adopt them? Some of them.

06-00:48:21

Lage: Did they adopt them --

06-00:48:22

Asch: Some of them. Some of them.

06-00:48:23

Lage: -- or was there discussion once it got to the top level?

06-00:48:24

Asch: Oh, well there was always discussion, and we didn't make recommendations. We did research. We were the staff. It was the commission that made recommendations. We were the staff to the commission. We couldn't make—it wasn't our role to make recommendations. We could try to be as persuasive as we could about why we thought the research did or didn't support a position, but it was the commission that adopted the position. And sometimes, actually, it was interesting. We didn't—as staff—always agree with the recommendations that the commission adopted, but our job was to write the strongest arguments for the recommendations that the commission came up with.

06-00:49:15

Lage: And you took up a whole range of issues, it seems.

06-00:49:17

Asch: Well, really just these three or four. Yeah. But we did the sort of life and death issues that bioethics did. We did surrogate motherhood and reproductive technologies, and we did a lot of these end of life kinds of issues, and I was putting forward my general critique, when it was appropriate. The surrogate motherhood stuff didn't have any particular disability implications. There were fascinating issues around surrogate motherhood, and should it be paid for, and should it not, and should a woman be allowed to change her mind in the middle of the pregnancy, or after the baby was born, and should you think about it as a contract, or should you think about it as adoption, and all kinds of

really important family issues, and who should get custody in the event of a dispute. Anyway, it was just great. It was just the most interesting intellectual stuff I had ever done, and these people were so smart, and actually, twenty years later, I still feel that bioethics is a great field. It has really smart people in it—and it has jerks and narcissistic and egotistical people, but it has a lot of really smart people thinking about important issues. I love the work. So I worked for the bioethics commission for three years, and then was laid off, and then I went back to New York to finish my dissertation, finally.

06-00:51:11

Lage: Which was on surrogate motherhood?

06-00:51:12

Asch: Which was on surrogate motherhood.

06-00:51:14

Lage: Did you choose that because of the work of the commission?

06-00:51:16

Asch: Well, yeah. I found it a really, really extraordinarily interesting topic, and I figured out a way to combine my interest in surrogate motherhood with a lot of my other interests, and designed a survey of people's attitudes towards surrogate motherhood, but also being interested in trying to show the similarities or dissimilarities between their attitudes towards surrogate motherhood and their other political beliefs.

06-00:52:04

Lage: Did you find a connection?

06-00:52:06

Asch: Yeah. Well, I did. I mean, this would be quite diverting, so I don't think I want to get into it in a lot of detail, except to say that there are people within bioethics today—because of sort of similar anger with the Bush Administration that many people had with the Reagan Administration—who think of a kind of left-wing and right-wing bioethics, and many people who think of a left-wing bioethics—if you believe in liberal social causes—this is a claim—if you believe in women's equality, if you believe in ending racism, if you believe in a right to healthcare, if you believe in alleviating unfair differences in the life opportunities of people based on their wealth, you'll also believe in biotechnology as a way to ameliorate human problems, and so you'll support stem cell research, or genetic screening, or physician-assisted suicide. The so-called view of left-wing bioethics is a belief in autonomy—individual autonomy—rationality, consumer control and choice, and the value of science and progress, and the claim of the left in bioethics—or the so-called left in bioethics—is that if you don't believe all of those things, you're part of the right.

So if you don't believe that physician-assisted suicide is a good thing because people ought to control the time and manner of their death if they want to,

you're denying people's autonomy and control. If you don't necessarily think that people should be able to select the sex of their child or create a child of one or another kind of characteristic, you're anti-technology, anti-progress, anti-choice, and anti-liberty. That's the left critique of the right.

I wanted to show in my dissertation—and I thought I could—that things were more complicated than that. That you could believe in liberty, and freedom, and equality and that you might balance some of those things differently in different contexts, and so the fact that you believed in individual autonomy might make you support a woman's right to be a surrogate mother, but if you also believed in certain kinds of equality concerns, you might be worried about who was doing the paying, and who was doing the being paid, and some of the class differences between rich and poor who were surrogate mothers—rich people hired them, and poor people were them. That was the claim. Now, I don't actually think that was true, but that was one of the concerns. I wanted to try to show that you could support surrogate motherhood or oppose surrogate motherhood, and still see yourself as a leftist, or a liberal, or a conservative for political reasons, depending on what your reasons were for opposing or supporting the practice. I wanted to show that things were more complicated.

And that's relevant to a lot of the disability issues in bioethics, as well, that I've worked on. I've really worked on two big strands within bioethics, some having to do with reproduction and family, and some having to do with disability. The disability issues come up a lot in the end-of-life context, and to some extent in the reproduction context, but there are some end-of-life issues that—well, obviously by the time you're dealing with end-of-life issues or dying issues, you're dealing with—obviously—sickness, and health, and disability. But they aren't about disability rights. And there are some reproduction issues, like surrogate motherhood, that aren't about disability rights, but then there are some that are. So one of the things that I've liked about doing bioethics is it's still very important within the disability rights context, but I'm also getting to think about other things. When I was doing the work on surrogate motherhood in New Jersey, and when I've been doing the work on surrogate motherhood, disability doesn't really come into it very much at all. If I'm doing work on end-of-life issues or some parts of the reproductive choice and prenatal testing, it will come into it. And so what I tried to do more and more, from the late eighties on, was move from disability rights activity into bioethics activity, and try to limit my disability rights work to bioethics-related work.

06-00:59:12

Lage:

I'm going to stop you right there. I'm sorry.

06-00:59:15

Asch:

That's okay.

End Audio File 6 asch_adrienne6_06-21-07.mp3

Begin Audio File 7 asch_adrienne7_06-21-07.mp3

07-00:00:00

Asch: I was saying how I was trying to limit the disability-related things I did to bioethics. Now, that hasn't always worked. Sometimes I get called—actually, it was funny. Last week, somebody from a Berkeley organization called the Center for Genetics and Society called me up and said would I come to a conference and talk about reproductive technology as it affected women with disabilities, and I said no. I said, "That's not the work that I do." And she said, "Yes, it is." And I said, "No, it's not. I talk about disability when it comes to using prenatal testing, but that's not primarily about women with disabilities." And she said, "Oh, yeah, right." I said, "Emily. You've heard me give talks on this topic. Where have you been? That's not what I'm talking about. If you want to have somebody talk about women with disabilities, call Marsha Saxton. She *is* doing that, but I'm not."

07-00:01:01

Lage: Now, give me the distinction again—what you do versus what Marsha does?

07-00:01:07

Asch: Well, I'm not particularly talking about how women with disabilities are affected one way or the other by reproductive technology. I'm talking about reproductive technologies and their effects on everyone, and that can include people who have disabilities, and it certainly includes people with or without disabilities using prenatal testing to decide whether or not to have a child with a disability. But that's not about women with disabilities.

07-00:01:44

Lage: I get it. That's very clear.

07-00:01:47

Asch: Well, you might think it's clear, but a lot of people don't! And I get called sometimes by people within bioethics—oh, this was really funny. Sometimes I'll get called by people within bioethics to give "the disability perspective on X." And I'll say, "Well, I don't know that there is a disability perspective on X. I might have my perspective, and it might be affected by the fact that I've thought about disability issues, but I don't know that it's affected the fact that I've thought about disability issues, and there is no disability perspective on X."

07-00:02:32

Lage: Tell me—this a diversion, but it's something I'm interested in. You were at a conference at Berkeley in the last year having to do with stem cell research.

07-00:02:45

Asch: Right.

07-00:02:45
Lage: Were you supposed to be giving a disability perspective on stem cell research?

07-00:02:48
Asch: Yes, and I refused to give it. Yes.

07-00:02:50
Lage: I missed your talk.

07-00:02:52
Asch: Well, I didn't give it, so --

07-00:02:54
Lage: Did you talk about something else entirely, or did you talk about whether there was a disability perspective?

07-00:03:00
Asch: No, I just told the organizers that if they wanted me to give that perspective, I wouldn't come, and if they wanted me to talk about stem cell research, I would, but I wouldn't talk about a disability perspective, because I didn't think there was one, and I wouldn't give it.

07-00:03:14
Lage: So you just talked more broadly about a --

07-00:03:16
Asch: Right.

07-00:03:17
Lage: A bioethical stance on stem cell --

07-00:03:20
Asch: Well, there are lots of bioethical stances on stem cells, some people who support it, and some people who don't. I said that I thought the basic issue in stem cell research for bioethics was not the ethics of embryos but the ethics of scientists, that scientists often made claims that they couldn't support for the outcomes of their research, and that I wasn't sure that the conduct of science to get its money was always ethical, so people would go to Congress and say, "We're going to cure Parkinson's Disease, or Alzheimer's, or diabetes with our stem cell research," and I said, "Maybe they will, maybe they won't, but they're overstating their claims, and many of those same claims were made by people about the Human Genome Project." When people went to Congress to get money to do research on the human genome, they said, "We're going to discover all the genes for all of these diseases and traits, and we'll find ways to cure them," and I said, "There are no therapies for genetic diseases and disabilities that have come out of the human genome project. There are more tests for more and more things. You can test for sickle cell anemia, or Huntington's Disease, or muscular dystrophy, or cystic fibrosis, or spina bifida, or Down syndrome, but there's nothing in the Human Genome Project that has cured any of these conditions or developed better treatments for

people with these conditions." Now, I think that's a very important point that needs to be made. It is a certain kind of disability perspective, but it's not as though there is one disability perspective.

07-00:05:24

Lage:

Right. How is it a disability perspective? Does it have to do with claims for cure?

07-00:05:30

Asch:

Well, it has to do with the idea that if you want to help people with these conditions, testing to make sure that more people won't be born doesn't help the people who are already living, and if you want to help people living with these conditions, medical treatment and cure is one way to help, but there are other ways to help that have to do with a fully accessible society, and a non-discriminatory society, and a barrier-free society, and affordable attendant services, and affordable healthcare services, and affordable public transit, and that if you want to improve the lives of people with disabilities, there are many ways to improve those lives that don't require curing the underlying disability.

And that's the perspective on reproductive issues and end of life issues, too, so that when you talk about Elizabeth Bouvia and whether she should be allowed to get doctors to help her die, the first thing is, "You wouldn't do that for a non-disabled person who is equally sad about her life circumstances. You'd give her psychological help and perhaps anti-depressant medication. So, do the same thing for this person with a disability. Then deal with the discrimination in her life." She was thrown out of school because she had a disability and they didn't really believe she could ever gain employment. She was denied attendant services in California to the level that she was actually legally due them. Change the bureaucratic hassles that she was dealing with, and give her the amount of attendant services she was legally due. If you want to make her life worth living, try to do those things. Don't say, "She has a disability. It would be awful to live like that. I don't blame her. I would want to die, too."

07-00:07:53

Lage:

So, by the same token, would you say that focusing—I'm thinking about the stem cell initiative in California—focusing on that in such a dramatic way, as California did and has takes away from other avenues of addressing illness and disability?

07-00:08:13

Asch:

Well, yeah. Resources aren't infinite, and the \$3 billion or whatever that has been allocated to stem cell research could be allocated to services, and medications, and family assistance for people with Parkinson's and diabetes and Alzheimer's, and all the things you're supposedly going to cure. Or you could divide up the money, and put only half of it into stem cell research, and half of it into social support or better drugs. I don't know.

07-00:08:55

Lage:

Is there a certain skepticism, do you think, for yourself and maybe others with disabilities about curing, about whether the cure's going to work?

07-00:09:03

Asch:

Well, I think there are a couple of things. This comes up in the cochlear implant debate, and in the sort of annoyance with Christopher Reeve. Christopher Reeve said, "I have all the money to buy all the equipment and attendant services I want, and I want to be able to walk. I'm never going to be happy as a person with quadriplegia. Don't tell me that I should be, or that I can be, or that I'm betraying other people with disabilities. I, Christopher Reeve, want to be able to walk again." Well, I think he had his right to say that if that's what he felt. I don't think he had his right to say, "That's what everybody with disabilities ought to want." I think it made Congress, and charity organizations, and non-disabled people generally feel better, because if you actually think that it must be awful to live as a person with a spinal cord injury, you'd much rather have somebody with a spinal cord injury say, "Yeah, you're right. It's awful. I want to be able to walk again," than say, "It's not so bad. I can live my life fine. Just give me a wheelchair and barrier-free buildings."

I mean, people, friends, whatever, professionals, have said, "Well, wouldn't you rather be sighted than blind?" And there are some people who would say, "No, I wouldn't." There are some people who would say, "Yes." And I would say, "I don't know that I care." If you gave me surgery tomorrow and I could see, that would be fine. I don't object to it. But if you made me promise that the price for the surgery was going on television and telling you what a happy person I was now, and that I'd been miserable for the last sixty years of my life, I would tell you to screw it. I don't have to be blind, and I don't have to not be blind. I'm sure I would enjoy things I could do looking at pictures if I were sighted, but I don't need to be sighted. I don't need not to be sighted. I don't think my emotional well-being will crumble if I suddenly see the dirt on the sidewalks. I don't think I have some deluded view of the world that's going to be radically changed if I notice how grimy the subways are.

07-00:11:52

Lage:

All things I've noticed the last few days.

07-00:11:56

Asch:

Nor do I think that my world's going to be so much better if I can walk faster from one side of a room to another, or pick up an earring when it drops if it doesn't make a sound. I mean, if the earring drops out of my hand on a carpet, and I have to kneel down on the floor and look for it, and you'll see where it is faster than I'll find it by looking for it—well, fine, but it's not a big crisis whether it takes me ten more tries to find the earring than it might take you. Now, this is actually a bioethically relevant statement, because bioethicists in their discussions of quality of life want to say—or many of them have wanted to say—"Well, if you have a disability, whatever it is—asthma, diabetes, spina

bifida—your life is less good than this so-called able-bodied person." And sometimes want to say that you should therefore be entitled to fewer social resources or healthcare resources, and that sometimes might mean—it came up, there was a California case with a woman named Sandra Jenson who had Down syndrome and was denied, for a while, by several different transplant centers an organ transplant, and the claims for her denial was that her intellectual disability would prevent her from complying with the treatment regimen, and there were also claims that organs are scarce resources and people who will have better lives should have them.

Well, those are both claims that I think are not morally acceptable, or even empirically acceptable. How do we know what's a better life? That's both an empirical and a moral claim. And why do we think that she couldn't comply with the treatment regimen? How much is that based on knowledge of her, or just some stereotype about people with Down syndrome? So, if people had come to me about that case—which they didn't—but if they had, I would have given those arguments about that decision. Now, I think eventually, some people in bioethics did give arguments that are similar to that, because she did get the organ.

The people who don't want me to debate with Peter Singer because they find his views about end of life and beginning of life very dangerous to people with disabilities—and I think they are. I think they're uninformed, and I think they're morally wrong, and empirically not supported. He's an important enough person that you have to debate him. You can't just say, "I won't debate him because I don't like him." I also think—and I said this in the debate—that focusing on Peter Singer is not the right thing to do, because Peter Singer is not alone in these beliefs. Lots and lots of people in the general public believe these things, lots of people within bioethics believe these things, so you have to fight about the ideas, not the person who's espousing them. He shouldn't be the locus of all of this anger.

07-00:16:12

Lage:

Is there something about him and the way he presents his arguments that makes him the locus?

07-00:16:15

Asch:

Well, he writes very well, and he's a very kind of charming, pleasant person, and he writes very accessibly to people. He wants to write so that anybody can read him, that you don't need a PhD in philosophy to understand what he's saying. So, his books are sold, they make more money than many other bioethics books, and people read them in college courses, and so I think that's why. And he tries very hard to communicate with the common people, as it were, or at least the *New York Times* readership.

07-00:17:11

Lage:

And what was it like to debate him? Is he respectful of his opponent?

07-00:17:17

Asch:

Sort of. We had met at a conference in 1998, at the International Association of Bioethics, in Japan. Actually, it was kind of funny. Neither one of us had anybody to have dinner with, I think because various people didn't want to have dinner with me, and various people didn't want to have dinner with him, so we wound up having nobody to have dinner with, so we had dinner with each other, and I said, "I'll make a deal." I said, "I really don't want to talk about all the things we don't agree about. We already know what they are, and I have no interest in talking about them over dinner, so we have to talk about anything else." So there was lots of other stuff to talk about, and that was fine. We're just about the same age, and his parents were Jews who emigrated from Germany to Australia to flee Hitler, and so we just talked about being an academic, or I don't remember what all we talked about. It was fine. I wasn't blown away by him. And then he said, would I be willing to come down to Princeton when he got there, and I said, "Sure," and I said, "Will you come to Wellesley?" I was teaching at Wellesley at that point. And he said, "Yes." So, we just agreed to do that. I didn't want to make a career of debating Peter Singer.

07-00:19:04

Lage:

Did you debate him more than once?

07-00:19:05

Asch:

No, not really. We debated in Princeton, and then he and I were on a panel at the American Society for Bioethics and Humanities in Philadelphia, and then I think there was one other sort of debate—it wasn't really quite a debate—in New Hampshire, put on by some New Hampshire Coalition of People with Disabilities, or governor's office, or something.

07-00:19:32

Lage:

That's the one that I read objections to. The Not Dead Yet group objected.

07-00:19:38

Asch:

To my doing that?

07-00:19:39

Lage:

Not to you specifically, but just the idea—I think it was a disability event, and having that at a disability event, that was their. . .

07-00:19:50

Asch:

Yeah, I don't know. I never read their objections. I remember when I was having dinner with Peter Singer, I was sort of amused. I thought it was sort of like CORE having dinner with the White Citizens' Council.

07-00:20:08

Lage:

Did you tell him that?

07-00:20:12

Asch:

Maybe.

07-00:20:15

Lage:

Did you get a sense of—well, we don't need to go into Peter Singer. I was going to ask you if you had a sense of where his views developed, but let's leave that for another time.

07-00:20:29

Asch:

I guess I get where his views—lots of people say things like this. I mean, Dan Brock, who's a Harvard bioethicist, and much more important in the bioethics world than Peter Singer, even though he's not a household word in the way that Peter Singer is, but if you want to talk about bioethics, he's taken very seriously. Dan Brock's views aren't very different from Peter Singer's views. They might differ in some ways. On this topic, anyway --

07-00:21:08

Lage:

This topic of right to life?

07-00:21:10

Asch:

Well, not right to life. I don't mean that. That's not the right way to put it.

07-00:21:16

Lage:

Well, yes.

07-00:21:16

Asch:

On the quality of life of persons with disabilities.

07-00:21:20

Lage:

I'm thinking of his views on, "It's okay to let the disabled baby die."

07-00:21:25

Asch:

Well, I don't know whether Brock would say that. He might or he might not. But he certainly would say, "Even if people are entitled to resources if they are alive and have disabilities," in his view, it's absolutely without question that their lives are less good than if they didn't have disabilities, and he thinks that's just an undeniable point. We got into a discussion about this six years ago at a meeting, where he gave a paper about how he thought it was morally required, even if not legally requirable, that fetuses be aborted if they were going to either have moderate mental retardation or blindness—and those were examples. He was using them as examples of all the disabilities that would lower the quality of life of people who had them.

So we had this debate. I said, "All right. So tell me. You're sitting in front of a real, live blind person. You've known me for ten years. Tell me how my life is worse than yours because I'm blind." And he said, "Well, it takes you longer to get places." I said, "Oh. How much longer does it take? What's your evidence for that?" And I said, "You have this statement in your paper, but you don't have any examples, and if you think that it will offend me to give examples, you couldn't possibly offend me any more than you already have. You might actually give me an example, and I'll agree with you. So, give me an example of why it's harder for me to live my life as a person who's blind than it is for you." And he said, "Well, I've seen you go places. It takes you

longer than it takes me to get from one place to another," and I said, "Well, maybe that's true, but has it stopped me from going any place I wanted to go, and what am I doing while it takes me longer? Are we talking about five minutes or five hours? Do I care? Does everybody who's sighted walk at the same speed? Do other people who are blind walk at the same speed? Maybe it has nothing to do with blindness. Maybe it has to do with my particular walking pace."

07-00:24:02

Lage: You say he's very respected in the field of bioethics, but his argument sounds rather childish.

07-00:24:10

Asch: It may be childish, but it's viewed as extremely important. I'm probably oversimplifying it, because I think it's so stupid and annoying. Again, it's a very widely shared belief.

07-00:24:33

Lage: Let's talk a little bit about the Hastings Center project on prenatal rights and the disability rights critique, because that sounds like an occasion when you got together with people from a variety of backgrounds and hashed over all of these ideas.

07-00:24:51

Asch: Okay.

07-00:24:54

Lage: And I know a book came out of it, but are there some behind the scenes discussions or interactions, or did any of your views evolve? Did you help other people's views evolve?

07-00:25:07

Asch: I think you would have to ask them. Okay. Erik Parens called me in 1994. I was teaching at Wellesley—no, sorry. I was teaching at BU. And asked me how I would create a project on prenatal testing, if I were going to create it. And so we started conversations. He wrote the grant, but I was involved in the conceptualizing of the grant that eventually resulted in the project. It took three years—three tries—for that grant to get funded, and I think one of the reasons that it took a long time for it to get funded—I mean, there might have been problems—he was interested in examining the view that I was considered sort of famous for having put forward, this so-called disability critique of prenatal testing. It's one of the things that I'm most known for publicly. Because the critique insists that professionals should be doing a different kind of counseling of women and couples than they typically do about life with a disability, a lot of professionals don't like it, because they think it's telling them how to do their job—which it is. They claim that it's information people don't want, because they come in for testing and counseling knowing what they already want to do, and they don't want information that will make them change their minds or reconsider what they

want to do, and my answer to that has been, "Well, then, you're not doing your job as a counselor." [telephone rings]

07-00:27:27

Lage: Okay, we're back on. Tell me who Erik Parens is. What's his background?

07-00:27:31

Asch: He's a bioethicist, or a philosopher. He has a PhD from the University of Chicago. I mean, people get into bioethics by a variety of routes.

07-00:27:47

Lage: Is he on the staff of Hastings Center?

07-00:27:49

Asch: Yes.

07-00:27:51

Lage: And you were saying that you had trouble getting it funded, but after three tries—who funded it?

07-00:27:58

Asch: Third National Institute of Health, Human Genome Project. And it's not uncommon for grants to be turned down the first time, for one reason or another, or even the second. But it's a controversial topic, and it's a controversial view within bioethics and within medicine that he wanted to study. The grant wasn't saying he supported the view. The grant was saying, "Let's try to understand the critique better, and think about whether we should change the way we conduct prenatal testing, based on the critique." We assembled a group of people to work on the topic.

When you say, "Are there behind the scenes discussions?"—we worked together very closely, picking people who should come to the meeting, and what topics would be at the meeting, and what background readings everybody should do who were going to be at the meetings, and what were the questions we wanted the meetings to explore, and what kinds of papers we wanted to have in the book, and then we had an email list serve, and people would send around comments about one thing and another that happened at the meeting, and go on. I don't know. Mary Ann would say, "Well, I didn't think, when Marsha said this," or Marsha would say, "Well, I didn't think when Mary Ann said this that she meant *that*. I think she meant something else, and I like it, or I don't." Just the sort of academic conversations you have when you're getting to know people and work with people. So, there were hundreds and hundreds of hours of conversations besides the meetings that took place. It was a very important project to me. I loved it.

Marsha Saxton brought together a not-so dissimilar group in Chicago in 1996 for a two-day meeting. It was different. I mean, there were a lot of meetings on genetics, and genetic counseling, and genetic screening, and genetic testing. Some with a kind of disability focus, and some not. The thing that was

really good about this Hastings Center project—we had good people who believed in talking and listening, and many of whom learned to have a good time together, even if we didn't always agree. That was the thing about the newborns project in 1984. That's the thing about all these Hastings Center projects. When they work well, you bring people together, and you may have enormous disagreements about things that matter a lot, but you can also find things in common, and you can laugh about things, and cry about things, and talk about things, and discover that even if you have huge disagreements, you have things to share as well, and I think that's very important, whatever you're working on with people, to find whatever common premises you have. It doesn't mean that you'll erase disagreements, but I actually think it's a very—I think it's a good strategy to try to understand people. What do you have in common? And if you have these ten things in common, why do you disagree on topic number 11? Now, I don't always think we get at that as well as I'd like. I really am interested in that question.

07-00:32:05

Lage:

Did you find that that happened a lot in this group? That you agreed on most issues, and then on another important one, which might be the crucial issue in that discussion—prenatal testing and how you counsel parents—that you have a basic disagreement?

07-00:32:32

Asch:

I think we all felt a lot of agreement on changing the practices of counseling. I think everybody came to agree that counseling should include a lot of information about life with disability. There might be disagreements about when people should get that counseling, but most people—I think—felt either before the project began or during it that counseling should include information drawn from however we think the social model of disability is. So it certainly should include, about cystic fibrosis was medications you need to—[knock at the door] Come in!

07-00:33:31

Lage:

Okay. We're back on. You were saying what? Genetic counseling for infants in case of cystic fibrosis, what it should include.

07-00:33:44

Asch:

Well, it certainly should include information about what the disease is. It affects your breathing, it affects your digestion, in order to keep your lungs clear, you may have to do a lot of physiotherapy every day. It can take a certain amount of time every day. There are a lot of medications you need to take. They cost this amount of money. Those are things that you need to know, that parents need to know about what's going to happen if they have a child with cystic fibrosis. But you also need to know, in addition to those things, you need to know how does it affect day-to-day life? Can my child go to school? Can my child go to work? How long is my child likely to live? What's the research on how it affects siblings? If they don't know those things, then they're not making an informed decision about whether to go

through with a pregnancy. When they get that information, it doesn't mean that they will go through with the pregnancy. I don't know what they'll do. But I think they'll make a decision with more information, and more careful information, than they had before.

Now, I think everybody who was on the project agreed with that. As I say, if they didn't agree with it before, they did agree with it by the end. I think what people didn't agree with—and actually, there's a paragraph in the book that says, "The deepest disagreement within the group is how—let's agree that a lot of the problems of living with a disability are socially constructed. How much of life with a disability is socially constructed? Is that really true about the nature of disability? The disability critique says it is, and medicine says it isn't, and how do we think about it? What is disability *really* like? How different is it to have Down syndrome from not having Down syndrome, and if it's different, how much can society change to make it less different? And even if society were utopian, would it still be different in negative ways?" What we said is that people disagreed about—I think two parts of that paragraph. One is how different it is now—and more negative or more difficult—and two, how much utopia—if we could ever get to utopia—would make it easier.

07-00:37:14

Lage:

Whether intrinsically --

07-00:37:16

Asch:

Right. And when I started teaching my course, called *The Disabled Person in American Society*, the overarching question in the course was, "Is disability inherently, inevitably, intrinsically different from not having a disability? Is it modifiable? Is it changeable? What's intrinsic—are the negative parts of disability inevitable?" I'm not saying it as well as I could. I think we don't have anything close to an answer, because we're so far from living in a non-discriminatory society that we'll never know that. And I think people within the world of disability might give very different answers. My answer is first of all that I don't know, and second of all that it doesn't seem—when people say, "Wouldn't the quality of anybody's life with a disability be better if they didn't have the disability?," my answer is, "It depends on what dimension you're using for the word 'better.' And it depends on how much that dimension matters to you." So, you could say to me, "Would you like to have more money than I have now?" Well, maybe. Or you could say to anybody, "Wouldn't you like it if you got a raise?" Well, yeah. I mean, I suppose it would be nice to have more money, but do I know exactly what I would do with it if I had it? Do I have a particular plan? I mean, I might have more choices I could go to fancier restaurants. Do I need to go to fancier restaurants? Maybe, maybe not. It depends on how important it is to use money in a particular way.

Erik and I had an interesting conversation at one point during the project where he said, "Look. Come on, Adrienne. Every parent wants their kid to be able to walk. What's wrong with that?" And I said, "Well, every parent wants their kid to be able to have experiences, and some of them have to do with getting from place to place, and so if you can't walk, and you use a wheelchair, or crutches, or a gurney, you want to get from point A to point B, and so parents want that for their kids." Walking's nice if you can do it, but does that mean everyone has to walk? It's not obvious. I think for Erik—who's very sympathetic to the disability critique—that's still a kind of stretch. He thinks my answer is kind of silly—or, not silly. He thinks I'm probably going too far in that answer. Like, "Come on, Adrienne. Just say it'd be nice to be able to walk." Or, "Just say it would be better to live longer than not. If you have cystic fibrosis, wouldn't it be better to know you're going to live seventy years instead of thirty years." And I won't say that.

07-00:41:18

Lage:

It seems to me—as a non-disabled person—that my desire is to draw a line between what I would see as an illness versus a disability. Like, something like cystic fibrosis that requires constant medical treatment and really seems like more of an illness. Is there any --

07-00:41:39

Asch:

I think it's dangerous to draw that line. Because first of all, politically, if you want as a disability rights movement to speak for millions of people, lots and lots of people with so-called disabilities have illness that need medical attention in addition to those disabilities. So, you'll lose millions of people—diabetes, arthritis, asthma, cystic fibrosis—but even parts of life with quadriplegia or paraplegia include the need for medical attention, if you get a bed sore, or if you get respiratory complications, or whatever. I think it's politically dangerous, and in some ways for some purposes conceptually dangerous—there are points—you know, you have to treat cystic fibrosis medically different from how you would treat quadriplegia. So, they're not all the same. But if you want to make a society that is inclusive, and as inclusive as possible—which is the goal, I think, of the disability rights movement, that has to include people who have illnesses, and what you want is to be able to say, "Okay, yes, you have an illness—in the case of diabetes or cystic fibrosis, you have a chronic illness—that may eventually kill you. I mean, you might get hit by a truck, but if you're not hit by a truck, or if you don't get cancer, you might die because of diabetes or cystic fibrosis. Okay. But before you're dead, you're alive. Let's make life as good as possible." That means doing what you can to resolve the illness, and also helping people with the illness live as good lives as they can while they're ill. And in that sense, it's exactly the same as the so-called disability rights movement, and I think the disability rights movement will do serious damage to itself if it thinks that it's just talking about people with mobility impairments, or deafness, or blindness, or cognitive disabilities, or autism. It's not true.

07-00:44:08

Lage: I think we started today's conversation with you're saying this is a very big tent that you envision, which is also --

07-00:44:16

Asch: Yes. And the *law* envisions it! The Americans with Disabilities Act envisions it. The courts are trying to narrow it, but the cases that were brought under the Americans with Disabilities Act of people with diabetes or epilepsy, they have impairments that affect a substantial life activity—or people's perception of it, anyway.

07-00:44:44

Lage: Do you see any distinction with illnesses that come on late in life, like Alzheimer's and Parkinson's, most often?

07-00:44:52

Asch: No. Why would I—I mean, there's --

07-00:44:55

Lage: I don't know. I'm just asking.

07-00:44:57

Asch: That is, there are lots of distinctions to make, but not in the general approach. That is, if you acquire an illness—like Parkinson's or Alzheimer's—you lose certain capacities that you had—stamina, memory, whatever. Now, everybody who ages loses some capacities. Maybe you lose more of them, and maybe you lose more of them faster, but it's a kind of hastening of an aging process that people are going to go through, and you have to adapt to losing capacities that you had, and the people around you have to adapt. And sometimes, people say, "Well, it's easier to—" in the same way that it's better to have loved and lost than never to have loved before—that sort of cliché? People are always doing that about life with disability: "Well, is it better to be born disabled, or to get it later?" I actually think those are dumb questions. It's another one of these "better." It's *different*.

If I had been able to see, and I no longer could see, I'd have certain memories of color and shape that I might not have now. Maybe that would be good, maybe it wouldn't. Maybe I wouldn't care. Maybe I'd care a lot. I have no idea. Some people care, some people don't. If I became mobility impaired tomorrow and could never walk again—I mean, I like walking. It's fine. Would my life be traumatized because I couldn't walk? I don't think so. It's actually complicated to use a mobility cane and a wheelchair, but I've done it, and you can learn how to do it. I mean, just to give you that kind of trivial example. If I got Parkinson's, I'm sure I wouldn't like being sick, but I'd do my best to adapt to whatever changes. Now, anybody who gets an illness, whether it's a back problem or Parkinson's, it affects their life. It affects how they do things. If you get a back problem and you can't lift fifty pounds, well, then you have to figure out how to lift whatever you were lifting before. Either somebody else has to lift it or you have to get a piece of machinery to do it, or

you have to find some other way to do the thing you were doing otherwise. If you have Alzheimer's or Parkinson's and you lose memory and agility, you'll lose certain abilities that you may have liked, and you'll have to develop other things to do, but everybody has to develop other things to do. I mean, you age, and you can't run as fast as you could run twenty years ago, or you can't hear as well, or you can't remember as much, or you can't stay up all night, and you need more sleep, or I don't know, whatever. Everybody—life is full of things that you have to adapt to.

07-00:48:28

Lage:

As you talk, it strikes me—this disability perspective, it has a lot to offer people aging. Many people who don't consider themselves disabled, but face these limitations.

07-00:48:49

Asch:

You know, all the people whose pensions were taken away from them because of unscrupulous employers like Enron—that was horrible, and they shouldn't have had to adapt because their money was stolen, but you live in a war-ravaged country, and you have to adapt. Ideally, we shouldn't have war, but if we have war, you have to figure out how to live with it. It's not different from lots of other things that happen to people. You have a job, and you lose it for some reason, not of your own choice, or you're living with someone who gets a promotion and wants to move to a different city, and you have to figure out how to maintain your relationship, either staying in different cities, or both of you moving and one of you changing jobs, or whatever.

Life is complicated. You have to adapt. I don't think disability is on some continuum different from lots of other things that people have to adapt to. And I think that's both a disability rights perspective and a bioethics kind of perspective.

One of the big debates within bioethics—here's an example. It came up with prenatal testing. Some people would say, "Well, let's draw a line. It's fine to test and abort for Down syndrome, but it's not fine to test and abort for sex. Sex selection's bad, because it's as good to be female as it is to be male, and it's as good to be male as it is to be female, but it's better not to have Down syndrome."

And I said, "Look." And I still maintain this. I said, "Look. If you want testing to be up to the people who are doing the testing, and up to the people making the decisions, you can't draw a line. You have to say, 'Let people make whatever decisions they're going to make.' And probably more people will test and abort for Down syndrome than will for sex, but if you make a list of the things that it's not okay to abort for, or not okay to commit suicide for, and then you make a list of the things that it is okay, then you will be saying what you claim you're not saying. You claim you're not sending a message to anybody about whether it's good to bad to have this disability. You're trying to

just give people information and let them make decisions. Well, if you don't want to send any messages, then don't make any lists. Give people information, and let them make their own lists of what's acceptable to them and what isn't."

07-00:51:56

Lage: But drawing those lines is where it starts becoming a societal judgment.

07-00:52:00

Asch: I think it would be better if we weren't doing this kind of selecting, but if we're going to do some selecting, then I think we have to be allowed to do any selecting we want. Because then if you do draw lines, then you are making a societal judgment about what's beyond the pale and what's okay. Now, does that make any sense to you?

07-00:52:23

Lage: It makes a lot of sense. How does it fit with the pro-choice feminists? How do they approach these--

07-00:52:30

Asch: Now, wait a minute. You aren't asking that because you don't understand it.

07-00:52:33

Lage: I'm asking it because I want you to talk about it.

07-00:52:36

Asch: But I've been *saying* how it fits. I've been answering how it fits. People get to make whatever choice they want, but they have to make an *informed* choice.

07-00:52:56

Lage: You're staunchly pro-choice, it sounds like.

07-00:52:59

Asch: Yeah.

07-00:52:59

Lage: You know, one thing I enjoyed reading, I found on the web—now I have to find out exactly what it was—a *Ms. Magazine* conversation in 1997.⁶ Would you have some background on how that came about?

07-00:53:19

Asch: I got called and asked to be part of it. This is another one of these, "We want the disability perspective on choice!" But that was fine. I thought it was an important venue, and I also thought they were bringing very good people together to talk about pro-choice, and I also thought I had things to say that weren't only about disability, and it seemed to me that I did. I tried to say,

⁶ Marcia Ann Gillespie, Frances Kissling, Faye Wattleton, et al, "Speaking Frankly," *Ms.*, May/June 1997, vol. 7, p 64.

"Look, if you want to have choice, that's important, but having choice doesn't mean pretending that fetuses aren't biologically alive. They're not rocks."

07-00:54:01

Lage: And it seems that you were one of the ones that really made that an issue that had to be attended to in that discussion.

07-00:54:12

Asch: Right.

07-00:54:14

Lage: And I don't think the pro-choice people really want to talk about that.

07-00:54:19

Asch: Well, I think they don't, but I think they're making a mistake.

07-00:54:21

Lage: But they did, in this conversation.

07-00:54:26

Asch: Yes, I am staunchly pro-choice, and I don't think there's any problem about—I don't see this as paradoxical, contradictory, anything. I'm accused of that, but I think that's by people who don't understand what I'm talking about, and haven't paid attention, and the reason I said that when you asked the question, I thought I'd been answering that for the last forty-five minutes, so it— anyway. The same in terms of physician-assisted suicide. I don't think it's a good idea to legalize physician assistance in dying. I think we're a long way from having the kind of rights to health care, and rights to good quality care, and pain control, and understanding of life with illnesses and disabilities so that you do have people making decision because they're afraid, because they don't want to burden their families, because they think they might be abandoned when they become very ill, or have serious disabilities. And instead of wanting to die, I'd rather have people help themselves figure out how to live. Now, at the end, after we did all those things, if people still wanted to die, well, people commit suicide. I can't stop—the person who commits suicide commits suicide. [telephone rings.]

End Audio File 7 asch_adrienne7_06-21-07.mp3

Begin Audio File 8 asch_adrienne8_06-21-07.mp3

08-00:00:01

Lage: Continuing with tape eight.

08-00:00:04

Asch: Let me start, actually, with SDS [Society for Disability Studies]. Irv Zola founded the *Disability Studies Quarterly* in about 1983. It was called then the *Disability and Chronic Disease Quarterly*, and I remember sending him a note saying, "I think you should call it 'Disability,' rather than 'Chronic Disease,' because chronic disease is still a disability under the rehab act, and even

though chronic disease could be progressive, as a political entity, it's still disability for political purposes, and for movement purposes." I don't know whether that's what got him to change the name, but he changed the name to the *Disability Studies Quarterly*.

There was a Western Social Science Association group called the Society for Chronic Illness, Impairment, and Disability that brought together sociologists, mostly, that Irv was part of. He didn't start it. Gary Kiger and Steve Hey and Daryl Evans were three of the originators, and other names that you may or may not have heard—Nora Groce, Elaine Makas, Caroline Kaufmann, Cary Kaufmann were among the people. These were all sociologists, and social psychologists, and anthropologists teaching at different universities who had done research on disability topics. Cary, and Daryl, and Irv had disabilities. I think the others did not. But they were all interested in the social aspects of disability. I went to a conference in 1985 in Fort Worth, of that Western Social Science Association.

08-00:02:26

Lage:

By "Western," did they mean Western US?

08-00:02:28

Asch:

Yeah, Western US. Of this Society for Chronic Illness, Impairment, and Disability. So I went in 1985, and I went in 1987, and somewhere around there, those people said, "Let's form our own organization, and let's call it SDS, the Society for Disability Studies, and then we can use our SDS buttons from the 1960s." And we all liked that, because it was people who had been quite left-wing, and had a very left-wing approach to politics in general, and had a sort of social disability rights approach to disability.

08-00:03:30

Lage:

Did that earlier group, the Western Association, have a social disability rights approach?

08-00:03:35

Asch:

Well, this little group did. I mean, the association was just a regular academic association, but the group of us who met as the Society for Chronic Illness, Impairment, and Disability, yes. It was the same people. But we were only thirty or forty people, or something. So they founded this Society for Disability Studies. I didn't go to the 1988 or 1989 meeting. No, sorry, I did. I didn't go to the 1988 meeting. I did go to the 1989 meeting, and in fact, I think that 1989 meeting was in Denver, and part of it included a group of people who were talking about bioethics and disabilities, as a matter of fact. And it had some people from Europe, who had been starting—by the time of 1989, I was really fully involved with bioethics, and disability issues, and these reproductive issues, and in these sort of end of life issues. There were enough other people—Harlan Hahn came to that meeting, I think, and many other people came, and talked about these same kinds of things that I'm talking about. And then I think I went to the 1990—I don't remember whether I went

to the 1990 meeting. I don't think I did. My job was very demanding, and I didn't have a lot of time to go to meetings.

Anyway, I continued to be involved. I read *Disability Studies Quarterly* all the time, and Irv would have me write book reviews, or articles, and I was doing enough publishing of articles here and there that I was known as an active person within the disability scholarship world, even though I was still finishing my PhD. I forget when I got asked to be on the board of SDS. I think it was originally—I think I was on from '90 to '93, but I said that I wasn't going to be able to do a whole lot. I would try. And I didn't do very much, actually. But then by '93, I had finished my dissertation. I had my job at Wellesley, and so I started getting—not only going to meetings, but just being more involved with the organization. I don't know. Anyway, I can't remember when I then got on the board again.

08-00:07:42

Lage:

I have—from your vita—'95 to '98, you were on again?

08-00:07:46

Asch:

Yeah, well, that was—I think—my second--

08-00:07:49

Lage:

Second time around, yeah. '90 to '93, and then --

08-00:07:51

Asch:

Right. And then '95 to '98. Okay, so '95, I got on the board again. I think Richard Scotch was president in 1995. Yeah. And then I think Corinne was—Corinne Kirchner—was president from 1995 to '96, and when her term was going to end, I think she asked me if I would be president next. I had some misgivings about it, but I said okay, and my misgivings were not a matter of anything except how much time did I have to give to doing it. But I really liked the organization, and believed in it, and liked the people. It was a very good organization. So I said yes. So I was president from '96 to '98.

They were then getting to be two kinds of tensions within the organization that I really wished hadn't been the case. One was between academics and activists. Well, actually three: academics and activists, the role of non-disabled people within disability scholarship, and social science and humanities. Well, you won't be surprised to hear from everything that I've said in the last ten hours that I thought those were very detrimental to the organization and to the world of disability studies. I mean, I thought we needed activists and academics, and I thought we needed social scientists and humanities, and I thought we needed people who wanted to do good disability scholarship.

There were a couple of horrible moments where people accused some various non-disabled scholars in the organization of—I don't know—not being legitimate, and how they shouldn't do it, and their jobs should be done by

people with disabilities, and only disabled people could teach disability studies, and I made it very clear that I just thought that was plain wrong. If you're going to do oral histories of people, I hope you're going to do Mary Johnson, if you haven't yet.

08-00:10:36

Lage: We haven't yet, but she, again, is on our list.

08-00:10:38

Asch: Well, she's a good example. I mean, Mary Johnson, and Alan Gartner, and Richard Scotch would be people I think should be on your list for people to do.

08-00:10:53

Lage: And how do they come up in this context?

08-00:10:55

Asch: Well, they come up in this context, because they're among my examples of—I think—some of the finest people doing disability activism and scholarship, and policy, who don't have disabilities, but they're really committed, and they really are sensitive to the issues, and believe in them, and I think that's critical. So I found the splits very, very distressing.

08-00:11:30

Lage: And were they open?

08-00:11:32

Asch: Yes, they were open.

08-00:11:33

Lage: Open at conferences --

08-00:11:34

Asch: Yes.

08-00:11:35

Lage: -- or in board meetings?

08-00:11:36

Asch: Conferences.

08-00:11:37

Lage: Conferences. That must have been --

08-00:11:40

Asch: And they didn't tear the organization apart, but people said mean things.

08-00:11:47

Lage: And how was it resolved? Did you have a role in trying to --

08-00:11:51

Asch: Well, I'm not sure that it --

08-00:11:55

Lage: Maybe resolution isn't the right word. How was it dealt with?

08-00:11:57

Asch: I forget. There was one moment where people criticized somebody, and I got up, and said, "I just think you're wrong. I'm just going to say right now, I think this is bad. I think it's detrimental to what we're trying to achieve here, and I don't think it's necessary." But I was one person. I was a person that many people took seriously, but lots of people don't.

08-00:12:30

Lage: When you say a split between academics and activists, was it wanting the academics to also be activists? Was that part of it?

08-00:12:42

Asch: Some of it was sort of being skeptical of academics. Some of it was people being nervous about research, and any kind of scholarship, and sort of saying, "We don't need scholarship. We need advocacy."

08-00:13:01

Lage: Although it was the Society for Disability *Studies*.

08-00:13:04

Asch: Yeah, well. But some people thought of it as the Society for Activist Disabled People, or—you know. And some people thought of it as the Society for Disabled Scholars.

08-00:13:17

Lage: I see.

08-00:13:24

Asch: And then—and this I have found also kind of annoying—there are some people who—cultural studies is a very big thing, and there are a lot of people doing very good work on cultural representation, and images, and this and that. I think that's fine, but I think we still need empirical research, and social science, and social policy. I don't want to see fields totally dominated by any one perspective. When I taught my course on abortion at Wellesley—I taught a semester course on abortion, and I loved teaching that course, and it's just one example. It was called, "Multi-disciplinary Approaches to Abortion," and I used—and this was true in all of my courses that I taught at Wellesley—I used philosophy, I used law, I used literature, I used autobiography, I used psychology, and sociology, and history, and anthropology to look at a question. And that was the same thing that I did when I developed my Disability in Society course. I used all of those perspectives. It's the same thing that I try to do in all of my teaching. I don't think you learn about a problem by using only one method of looking at it. It's why I'm a very interdisciplinary academic. Even though I have a PhD in social psychology, I'm not in a social psychology department. I haven't been in a social psychology department ever.

08-00:15:01

Lage: And that's by choice, it sounds like.

08-00:15:03

Asch: Yes. Well, nobody would hire me in a social psychology department, because I don't publish in social psychology journals. But I'm not really a traditional social psychologist. I don't do experiments. I don't do mostly empirical research. I mean, more and more, I do bioethics. But I think there are many ways to look at a problem, and I'm actually not looking at being a philosopher, or a lawyer, or a social psychologist. I'm interested in studying certain kinds of social problems, whether they're about bioethics, or disability, or social policy, or war and peace, or abortion, or whatever they are. I'm interested in questions, problems.

08-00:15:56

Lage: And bringing a lot of different approaches to bear on them?

08-00:15:59

Asch: Right. And so one of the things I loved about the Society for Disability Studies when I was more active in it was that you could go to a meeting about—I don't know—the college experience, and you'd get someone talking about being a college student with a disability, or being a professor, or somebody who had done research on surveying college students, or college administrators, or who knew what. You'd get all kinds of things. And that's the same thing at the American Society for Bioethics and Humanities. It's a very interdisciplinary organization. You have people who study bioethics issues using literature, and you have people who study it using religion, and people who look at it through law, and people who look at it through philosophy, and people who look at it through history, and social science, and—I don't know—economics. I like that. I think that's great.

08-00:17:06

Lage: So, these three issues that came up—I can see why they'd be disturbing to you. They were all challenging things that you held in a rather serious way. And as president, did you make any effort to have the society focus on those three issues in a formal way?

08-00:17:31

Asch: Well, we had a retreat the last year. The one thing that I did as president—that was during the prenatal testing project—we brought the prenatal testing project to the society, and we had some symposia on the prenatal testing project issues during the SDS meetings, and the really great part of that was that all these people who had done bioethics but had never kind of hung out with people with disabilities in the bar just got to go be at an SDS meeting, where you had three hundred people, and half them had visible disabilities and were using crutches, or wheelchairs, or interpreters, or whatever, and they got to experience an organization that was committed to access, and committed to inclusion, and it was a serious academic organization. And I think people liked it. I think people did like it. That was one of the most important things I

did as president, was set that up. And then we did have this retreat, trying to figure out how to acknowledge the existence of those tensions, and also just think about where was the field, and where did we want it to go.

08-00:19:07

Lage: Who took part in that?

08-00:19:09

Asch: The board. Yeah. We had a board kind of day retreat, and then we published position papers that we had written in *DSQ*, but I don't know that anything necessarily happened with that. To some extent—it's ten years ago, and I think a lot of people have made peace, and then some people have gone into other directions. There are more activists, and artists, and performance artists, and literary studies people doing disability studies at the society than there used to be, and I think that's fine. I think it's unfortunate that some of the people like Corinne Kirchner, and Shari Barnhart (spelling?), and Lynn Schlesinger, and Barbara Altman, and Richard Scotch have stopped going.

08-00:20:18

Lage: And why have they?

08-00:20:19

Asch: Well, I think they've stopped going either because their research has gone in some other directions or because they're tired of the fights about whether non-disabled people should be allowed to do disability studies, or whether the social sciences matter, or because they felt the quality of the papers was getting worse and worse, and not interesting to them anymore.

08-00:20:45

Lage: Do you think the quality has diminished?

08-00:20:47

Asch: Well, I haven't gone in a couple of years, and I am going to go again next year, probably. I think the last time I was there was 2003, and some it was all right, and some of it wasn't. The reasons that I haven't gone aren't lack of interest. I mean, I am going more and more to bioethics things, and there are so many bioethics conferences. An example: I'm going to two bioethics conferences in the next month on end-of-life issues. Now, these are bioethics conferences that are explicitly trying to bring together many perspectives, including very, very consciously disability perspectives, so ADAPT [Americans with Disabilities for Attendant Programs Today] and DREDF are going to be at both conferences, and Not Dead Yet. And I think that's really good. And I think even though I'm one of the not too many people who routinely goes to bioethics conferences who's viewed as having a disability perspective—I'm still one of the ones most often called to get "the disability perspective" on whatever the bioethics topic is. That's partly because people know me, and they're used to me, and it's partly because they associate me—sometimes much too much—with that. I don't get called as often to give a perspective on some other non-disability reproductive issue, but I do

sometimes, and this goes to my academic career. My academic career has been—it's now fifteen years of full-time university professorship: two years at Boston University at the Social Work School, eleven years at Wellesley --

08-00:23:01

Lage: Eleven years?

08-00:23:01

Asch: Yeah.

08-00:23:04

Lage: '94 to --

08-00:32:05

Asch: 2005. And then two years here. At Wellesley—which was a very important thing—

08-00:23:20

Lage: Just tell me how that job came about.

08-00:23:23

Asch: Oh, that's a great story. I was sitting in my house grading papers, and I got a phone call, and my friend David Osher called up and said, "Adrienne. I've just seen an ad for a job you should apply for." And I said, "But I'm not looking for a job." And he said, "Listen to this ad." And I said, "I'm going to apply." He said, "Well, you have a week!" He had seen the ad in the American Historical Association newsletter. It was an ad for a person to design a program called "Biology, Ethics, and the Politics of Human Reproduction" at Wellesley. I forget all of the things it said in the ad—you know, work at a small liberal arts college, do research and teaching, work with students, work with faculty, encourage collaboration, develop programs. I didn't know too much about what that really meant, but --

08-00:24:39

Lage: Sounded good.

08-00:24:40

Asch: It sounded good to me. So I got my resume together, and I wrote a cover letter, and thought about it a lot, and got three people to write letters of reference, and sent it off, hoping—I was two years out of my PhD. I hadn't done a fabulous job at BU, but I was doing okay. This was a job that it seemed to me was one I could do, but I didn't think I could get. I didn't think I could persuade anybody that I was ready for this job, and I also didn't quite know what it all meant.

08-00:25:45

Lage: There probably weren't too many professors in biology, ethics, and the politics of human reproduction.

08-00:25:50

Asch:

Well, there were forty applicants, because it was a very—there were all kinds of people. There were people with philosophy backgrounds, and people with law backgrounds, and people with social science backgrounds who had the same appreciation of interdisciplinary work that I did, so they had forty applicants. I don't know anything about most of them. I subsequently learned that they had hired somebody for the job who had then turned them down, and I know who they hired. They hired a very prominent bioethicist named Lori Andrews. She had originally accepted the job, and then decided for various reasons not to take it, and so they started a new search. It's totally a miracle that I got called by my friend David. I would never have seen the ad. I wasn't looking for jobs. I wasn't reading the *Chronicle of Higher Education*. I wasn't reading—I just wasn't reading job ads. I had a job, and --

08-00:26:55

Lage:

And only two years into it.

08-00:26:57

Asch:

And I was only two years into it, and it was a tenure track job, and it was in a perfectly good enough place, and so then I got an interview for the job, and I went and had this day-long academic interview, and one of the things I realized was I really wanted this job. Oh, boy, did I want this job. It was kind of scary how much I wanted the job.

08-00:27:29

Lage:

Now, was it the interview? The people you met?

08-00:27:32

Asch:

Well, it was a combination. I mean, it was the interview, it was the people I met, it was realizing—when I wrote the letter applying for the job, I said, "If I had been asked to design my dream job, this probably would be it." It was designing courses in bioethics, and because I'd gone to Swarthmore, I believed a lot in liberal arts colleges. I thought they gave you a chance to know students well, and for students and faculty to know each other, and to build a kind of community that I really liked the idea of. So although I wasn't so enamored of the women's college thing, it was still a small, good liberal arts college, and it was in the Boston area, so I didn't even have to move, although—

08-00:28:29

Lage:

Oh, that's right. You were right there at Boston.

08-00:28:30

Asch:

I actually did move from Boston to Wellesley, which was a mistake, but I did.

08-00:28:39

Lage:

So you realized how badly you wanted the job.

08-00:28:42

Asch:

And I got told a week later that I had done a good interview, but I hadn't been sort of glitzy enough—this was just a rumor. They weren't sure I was going to get the job. And I was disappointed, but there was nothing I could do about it. They either were going to hire me or they weren't. I felt that I hadn't answered a question that they had asked me very well, and so I called them, and said, "I didn't give you a very good answer to one of the questions you asked, about how I was going to spend the program money, because I didn't realize there was a budget for programs, so now that I know that, would you be willing to let me write a proposal of how I would spend the money?" I said, "Or is that fair?" And they said, "No, you can write it." So I wrote this proposal, and anyway, I got the job. I was blown away. I was just blown away. I was so happy. I was just amazed, frankly. BU asked if there was anything that they could do to keep me, and I said no. I just knew it was absolutely going to be the right thing to do, and it was. It was fabulous.

08-00:30:34

Lage:

Was it an endowed professorship?

08-00:30:37

Asch:

Yeah. It was an endowed professorship for five years that could be renewed for another three. So I had this for eight years. And what the endowment meant was that I had a certain amount of money for program support, so that I could bring guest lecturers to Wellesley; I could pay for students to do some research, if I wanted them to collaborate or work on some project; I could create a small conference. You know, things like that. I also had the money to hire an administrative assistant and a researcher. So I had my own little teeny world to develop these courses and do whatever I wanted to do. I set up an advisory board of people on the faculty, and so for eight years, I did this program. And it was really fabulous. I designed courses on ethical and social issues in genetics, and I designed a course called, "Ethical and Policy Issues in Reproduction," which was all about infertility, and surrogate motherhood, and adoption. I designed a course on motherhood. I designed a course on abortion. I designed a general level bioethics course that covered non-reproductive issue topics. I co-taught a course on literature and medicine, and then right at the end, I co-taught a course on philosophy, politics, and disability, or something like that.

08-00:32:48

Lage:

What department were you situated in?

08-00:32:49

Asch:

I wasn't.

08-00:32:50

Lage:

Oh, you weren't?

08-00:32:51

Asch:

For eight of the eleven years, I wasn't in a department. I was --

08-00:32:57

Lage: You had your own little world, as you said.

08-00:32:59

Asch: And I worked closely with people in philosophy, and sociology, and women's studies, and biology, and psychology, and then I worked sometimes with people in anthropology, or literature, or whatever. But I wasn't in a department. And then after the endowment ended, what was worked out was that I would join the department of women's studies and teach similar kinds of courses, but then I was just a regular professor. And that was okay. It wasn't a great situation, because I didn't really teach my courses as women's studies courses. I actually would say things like, "Reproduction is not a woman's issue. It takes men and women to reproduce, and bioethics is not a woman's issue. So I think that how these things affect women is important, and this is a women's college, but my way of looking at questions is not, 'Is it good for women?'" That's *a* question, but it's not the first question, and it's not the only question.

08-00:35:00

Lage: And did that fit with the women's studies? I mean, did it create tension?

08-00:35:04

Asch: It didn't really create that much tension, but I didn't do that much with them. I basically just did what I was doing, but they wanted an administrative home for me. One of the other people in women's studies, whose passion was history of medicine, wanted to try to build a health and society major, or a kind of interdisciplinary major, but the college kept turning it down. They don't really like interdisciplinary majors, and they just kept voting it down. One of the reasons that I left was that I didn't feel that I could grow intellectually in that job. I could keep doing bioethics, and I could keep having colleagues all over the country, and go to meetings, but I thought it would have been really fun to develop a major in health and society, and that we had a lot of courses we could offer, and I felt the college was just being provincial and rigid in its attitude. I was really proud of the fact that some people developed their own independent majors in bioethics. I had some wonderful students. Some of them took one course, some of them took three or four courses with me. I had a very good experience at Wellesley. I got to develop collaborations, I got to develop courses that I think were very good courses. A lot of my students liked me. A lot of them didn't, but a lot of them did.

08-00:36:51

Lage: And did they like the courses? Were they courses that drew students?

08-00:36:54

Asch: Oh, yeah. Oh, yeah.

08-00:36:55

Lage: It sounds like it.

08-00:36:59

Asch:

And I got to do a certain amount of—there was this group called CARD, the Committee Against Racism and Discrimination, and it had faculty, students, and staff, and I got elected to serve a couple of terms on CARD, and that was nice. We tried to do some work on what we called the multicultural classroom—teaching in the multicultural classroom. So, we developed some faculty seminars on that. So I got to do lots of things that I liked, and I also liked the fact—oh, there was one day I was sitting at lunch in a group. I was sitting at a table in the cafeteria, or whatever, and somebody about two tables away was talking about teaching *Frankenstein* in a literature class, and I didn't know this person, but I asked somebody else who that person was, and they told me. So then I called him up, and I said, "Well, you know, I'm going to be teaching that book in my Ethical and Social Issues in Genetics class, and if you have been teaching it in your English classes, would you be willing to come do a guest appearance in my class and help lead the discussion?" And he said sure. And that was fun.

We didn't do that very often, but there things like that. There was somebody in Greek and Latin who came and did a guest appearance on the Roman family, and attitudes toward the family in ancient Rome, and how are they different from modern attitudes. If you like interdisciplinary teaching, it's just great to do stuff like that. So even though I wasn't in a department, I got known, and I had my enemies, and I had my friends, and I had a lot of students that I liked, and several students that I'm still in touch with who aren't students anymore.

08-00:39:32

Lage:

Why did you make the switch here? How did this job come about?

08-00:39:38

Asch:

This job came about an equally bizarre way. I was sort of getting tired of the situation at Wellesley. I couldn't advance. There was no way to make it a more complicated, interesting job. I was doing what I was doing, and I liked it, but I had done it. It was a small place, and even though I could go see colleagues all over the country, it's not the same as having them here, or where you work. And also, I wanted to do more other things. I didn't have a very balanced life. I was doing an enormous amount of work. I wasn't doing very much outside of work. I was seeing friends, but I wasn't doing any music, I wasn't developing my other political interests, I wasn't doing things related to progressive Judaism—just things that I wanted to do, I wasn't doing. So my aunt said, "You know, you really ought to write to Norman Lamm at Yeshiva University, and tell him you want to come back to New York, and he'll help you." And I said, "Okay." And then I didn't do it. And I didn't do it for like months.

08-00:41:10

Lage:

Now, why Norman Lamm?

08-00:41:11

Asch:

Because she knew him a little bit. She hadn't seen him in forty years, but she knew him, she thought he was a nice guy, he had been the president of the university, and for some reason that made no sense to me, she thought he would be interested. And I said, "Aunt Louise, this is not the way people get jobs in academia. There's no job." So after I didn't do this three or four times, she said, "You know, Adrienne, I'm really upset that you haven't done this." And I said, "All right. I'll do it, but I really think this is about the stupidest idea I've ever heard." So I wrote this letter that said, "Dear Dr. Lamm," or "Rabbi Lamm," or whatever, "You don't know me. I know you know my aunt, and I know you knew my father, but I realize I haven't seen you ever in my life, and I know you're not going to be the president anymore, and you probably have other things to do, but anyway, I'm writing to you because my aunt really thinks I should write to you, because I want to come back to New York, and I'd like to do more bioethics in New York, and I'd like to learn more about Jewish perspectives in bioethics, but I also know that you're retiring, and you probably have other things to do, so if you never answer this letter, I won't be upset."

08-00:42:49

Lage:

This is quite a letter! You protected yourself in many ways.

08-00:42:58

Asch:

Well, I just thought it was the stupid-- I just thought it was embarrassing. I just thought he was going to be appalled at getting this letter. So the next day, I got an email and a phone message that said, "Please call me, I want you to come to New York." And I just thought, "You've got to be kidding!" So I called him up, and he said, "I want to talk business with you. I want you to come to New York. I want to talk to you. I'll bring the vice president for academic affairs. We want to have a serious meeting with you." And all I could think of was, "Why?"

08-00:43:45

Lage:

Well, they knew you.

08-00:43:46

Asch:

No, they didn't! They didn't.

08-00:43:49

Lage:

Maybe they knew your work.

08-00:43:51

Asch:

They didn't.

08-00:43:51

Lage:

Oh, they didn't? Okay.

08-00:43:53

Asch:

No! They did not. The only thing they could possibly have done between the time they got that letter and the time that Norman Lamm called me up was

count the articles on my CV. They didn't read them. They've never read them -
-

08-00:44:08

Lage: Well, the title of your professorship [at Wellesley] was impressive: Henry Luce Professor of Biology, Ethics, and the Politics of Human Reproduction.

08-00:44:15

Asch: Well, maybe, but anyway --

08-00:44:16

Lage: Anyway, you tell me how your meeting went.

08-00:44:19

Asch: So Norman Lamm said, "Come meet me at this restaurant on 68th Street and Columbus Avenue." So I went to this restaurant, and there were these two people I had never met before, Norman Lamm—Rabbi Lamm, Dr. Lamm—and Mort Lowengrub. And Mort said, "What can I do to attract you to Yeshiva?" And I said, "I don't know, what are you talking about?" [laughter] And he said, "Well, we think that you could do all sorts of interesting things. We have a law school, and we have these bioethics people at Einstein, and do you know Nancy Dubler and Ruth Macklin?" And I said, "Sure." And then Mort said, "David Smith was at the Pointer Center in Indiana. I appointed him when I was the provost at Indiana University." And I said, "Oh, he's a fabulous person. He's really a great person, and the Pointer Center's a really good center." So I don't know what we talked about. We talked about whatever we talked about, for three or four hours, at this dinner. And they said, "We want you to come. Could you come in September?" And I said no. I mean, it was June.

08-00:45:39

Lage: It was June!

08-00:45:44

Asch: And also, they still didn't tell me what they wanted me to do. This was June of 2003. I said, "I don't think I could come in September, and besides, I've been trying to arrange for a sabbatical, and I finally have one, and I really, really, really want to have one, so I couldn't come until I have this sabbatical." So they said, "Okay." So then ensued several—then I didn't hear from anybody for a while, and I figured this was just a nice dinner, and I was never going to hear from them. And then in March of 2004, they had me come down and meet a variety of people, and give a job talk, and they said, "We want you to come. We found a donor to pay the money for your professorship." And I said, "Okay."

08-00:46:53

Lage: Does that mean they were creating a new position with --

08-00:46:58

Asch: Yes.

08-00:46:58

Lage: -- with the donated funds?

08-00:47:01

Asch: Yes. But they still hadn't told me what they wanted me to do, or where they wanted me to do it, or anything. So I didn't tell anybody, really, at Wellesley, or anybody else, that this was going on, because I just didn't believe it. And then I came down again in November of 2004, and met more people. I met people from the social work school, and the law school, and the psychology graduate program, and then it sounded as though they were really serious. They had me meet the president of the university, and he said, "Do you want to come here?" And I said, "Well, maybe. Sure." Then they offered me the job. They said, "We want you to come. You're going to be a University Professor. We don't know all of what you're going to do, but it'll be great. You'll love it."

08-00:48:01

Lage: [laughter] Did they offer you the opportunity to sort of design what you would do?

08-00:48:03

Asch: No. That's all they said. And then they said, "By the way, would you be willing to write us a proposal for a center for ethics?" And I said, "Okay." So I wrote—I'd never written a proposal for a center for ethics before. I didn't know anything about centers for ethics. I got on the web, and read all about all the other centers for ethics in the United States that I could find, and actually called David Wasserman, who is now my colleague, but he was at the University of Maryland. I called David Wasserman, I called Alan Gartner, and I called Betty Levin. They were three of my friends. And I said, "Can I talk to you about this idea, and will you look at my drafts and make suggestions?" And so I sent them my drafts, and they made very good suggestions, and I changed the drafts around, and two weeks later, I sent a proposal for a center for ethics.

08-00:49:02

Lage: Not bioethics?

08-00:49:04

Asch: No, not --

08-00:49:04

Lage: So it's broader.

08-00:49:05

Asch: Right. And I *loved* that. I just loved it.

08-00:49:10

Lage: Loved writing it --

08-00:49:11

Asch: No.

08-00:49:11

Lage: -- or loved the idea of the Center for Ethics?

08-00:49:12

Asch: I loved the idea of it. I loved the idea of working with law, and medicine, and psychology, and social work, and undergraduates, and coming up with kind of three different kinds of things: faculty research, graduate and undergraduate courses on different ethics topics, and public programs on big themes, or an ethics film series. Having a movie night, and having a panel talk about the ethical issues in the movie, or going to see a Broadway play that had a lot of ethical issues, and then talking about the play, and bringing scholars to campus.

So I wrote this proposal, and they liked it. So I had the job. I had *a* job, but I still didn't really know what the job was. And then I said, "So, do you want me to create this?" And they said, more or less, yes. So that was going to be part of my job, but I didn't know exactly how much of my job it was, and it's still been evolving. I started in July of 2005. I came down here. I left Wellesley, I came here, and started this job, which includes—in some ways, it's a lot like the Wellesley job. It has some teaching. It has time for me to do the kind of writing, and research, and traveling that I would do in any academic job. It has some program money to develop public events and bring people to campus. It includes developing a faculty seminar on some kind of theme. I've brought David Wasserman here to join me, and the other three people that you met—John, and Ari, and Stephanie—work in various both administrative and research capacities. So we're our own little crew here. We're the Center for Ethics at Yeshiva University.

08-00:51:32

Lage: Now, when you say you brought David Wasserman, were you able to effect his being hired here?

08-00:51:38

Asch: Yes. I was able to say, "If you really want this center—" I mean, I'd been here for a year, and I said, "I want to propose an additional staff member to do research, and work with me, and brainstorm, and be a real colleague, and they said okay.

08-00:51:56

Lage: And teach?

08-00:51:58

Asch: No, he didn't want to teach.

08-00:52:00

Lage: I see.

- 08-00:52:10
Asch: I asked him if he would be willing to do it, and I never, ever, thought he would say yes, because he had a job in Maryland, and his wife has a job, and he has two kids, and it's quite complicated for him. He commutes --
- 08-00:52:24
Lage: Oh, he commutes from there?
- 08-00:52:25
Asch: Well, he's here three days a week, and then goes home. And then they are going to move in a year, but he wanted his older son to finish grade school. And then we got a budget together for me to hire—I had hired Ari as a research and administrative assistant...
- 08-00:53:08
Lage: So, you hired David?
- 08-00:53:10
Asch: Hired David. I had been given the money to hire Ari as a research and administrative program assistant when I came, and that was a combination of reasonable accommodation, not—it was partly having someone to help me get stuff out of the library, and scan material, and read the mail, and stuff like that, and partly that if I was going to set up a program, I needed some support staff. And then as we got more and more ideas of things we wanted to do, I realized I needed more staff, or I wasn't going to be able to do it. So I've been given a budget that's mostly for personnel, but I have a quite high-level research assistant in Ari, a very overqualified administrative support staff in Stephanie, a PhD historian who's doing a variety of both research and administrative—kind of high-level administrative being a liaison to the development department of the university, and the communications department of the university, and PR, and stuff—and David, who's a colleague who's had seventeen years' research experience doing ethics and bioethics.
- 08-00:54:55
Lage: Ethics in general and bioethics?
- 08-00:54:57
Asch: Yeah. So this is a great little group.
- 08-00:55:02
Lage: Yeah. Is it a center yet?
- 08-00:55:05
Asch: Yeah, it's a center.
- 08-00:55:05
Lage: It's called a center.
- 08-00:55:06
Asch: I've got a brochure in a box. I think there's a box of stuff on the floor that includes a brochure. I'll give you a brochure. We have a website. We brought

a scholar in residence for three days, Michael Walzer, who's a political philosopher. He came and did a faculty seminar, and some class visits, and two big public lectures on war. We're planning a symposium on character and ethics in the presidency for next winter. And the thing that's great about this kind of thing—now, I'm not a scholar of war and peace. I don't know this literature. But I love the idea of getting to think about large topics and find people who are expert in them, and find other people on the faculty who are interested in them, and bring people together, and it's more interdisciplinary work, but it's even larger than bioethics. And I still get to teach bioethics courses, and be in a book group of people reading bioethics books, and do some bioethics work at Montefiore Hospital, with their bioethics people, and be on an ethics committee of a hospital. So I get to do all kinds of bioethics, and I get to develop all these interesting courses and collaborate. I mean, five of us are designing a course on professional ethics that we're going to teach at the law school next spring. I never taught a course on professional ethics, and I couldn't teach it by myself, but I don't have to. I'm getting to teach it with other people.

08-00:56:58

Lage:

It sounds very exciting as something to embark on after being eleven years in one place and feeling that you weren't growing.

08-00:57:07

Asch:

So it's fabulous.

08-00:57:10

Lage:

You mentioned yesterday or the day before that you'd just as soon not be teaching at a Jewish university. You didn't like the boxes. How does this being a Jewish university affect the --

08-00:57:22

Asch:

Well, it's very, very complicated. It's not quite true that I would rather not teach at a Jewish university. That's not quite what I said or meant to say. I didn't *go* to a Jewish university, and I didn't want to go to a Jewish university. In the same way that I understand why people want to have women's colleges, or Howard University—that's been a historically black college—or a Jewish university, or a Catholic university—I understand the reasons that people want those things, but I also think that if you want to live in a pluralistic society, you ultimately have to be able to deal with people who don't share some category of yours. But in the case of this university, its mission—or a large part of it, for undergraduates—is to educate people who want to be Orthodox. They want to make sure that there are no events on Shabbas. They want to make sure that there's food they can eat in their cafeteria. They want to have all the Jewish holidays off. They don't want to miss classes to observe Rosh Hashanah, and Yom Kippur, and Sukkos, and Simchas Torah, and Shavuot, and Passover.

08-00:59:37

Lage: I'm going to stop you right there. I'm sorry.

End Audio File 8 asch_adrienne8_06-21-07.mp3

Begin Audio File 9 asch_adrienne9_06-21-07.mp3

09-00:00:01

Lage: This is tape nine, and we're ready to roll.

09-00:00:08

Asch: So these are people who want to be educated in an atmosphere that is sensitive to and respectful of their religious practices and their religious sensibilities. There are interesting complications in creating a center for ethics in this milieu because one of the things that is important—it was true that I wanted to learn more about Jewish perspectives on bioethics topics when I wrote that letter, and I am getting a chance to learn some of them, because the students want to learn them. That is, they may be interested in knowing what other people think about bioethics, but they want to know what rabbis think. They want to know what Jewish law teaches, and so either I have to teach it myself, or have I to make sure that I bring in other people who do teach it. So I'm learning things about being Jewish that I never knew before. I don't have to accept them all for myself if I don't want to, but --

09-00:01:28

Lage: But it is part of your course?

09-00:01:29

Asch: But it's part of my course, and it means that I broaden my own Jewish education.

09-00:01:37

Lage: And is it an Orthodox—

09-00:01:39

Asch: It's an Orthodox institution.

09-00:01:43

Lage: Do they require that you present that point of view, or you just sense this from the students?

09-00:01:50

Asch: No, they don't require it, and if I were teaching—it also depends. In the law school and the social work school, which are nonsectarian—well, in the law school, nobody has to take a course on Jewish law. At the social work school, everybody—Jewish and non-Jewish—takes a course on Jewish social philosophy, and the theory is—and it's a perfectly good theory, as long as you know that you're going to do it when you come—even if you're not Jewish, it gives you a chance to think about one value system, and then you can think

about the value system that you have and that your clients have that might be similar or might be different. So it's not a proselytizing kind of thing.

Working with undergraduates who are Jewish and Orthodox is complicated. They do want to know what Halacha—Jewish law—says about things, and sometimes they're not really interested in learning outside of Jewish law, and I think that's a problem in a modern world in a country that includes very few Orthodox Jews and three hundred million other people. And everybody knows that. I mean, the president of the university knows that if you're going to run a liberal arts college with a very parochial student body, in a certain way, you are going to have tensions. And so for example, there are certain students who don't want to look at major historic works of art because they're nudes, or they don't want to read sexually explicit novels, even if they're considered great novels.

Well, those are debates that are going on on the campus, and in fact at some point, the Center for Ethics may help sponsor a public dialogue on the liberal arts at a Jewish university. Having come from a very different approach, that reveres the liberal arts, and reveres open inquiry, I could be very angry and scoff at this—and it's easy to do that, or just to find the whole thing rigid and wrong—but what I've been coming to understand is that although I think there are problems with some of that approach of not wanting to see pictures or read literature, Ari was really great at saying, "The notion of modesty that's very important within our practice, it's about what experiences you have. It's what you expose yourself to. It's not about covering yourself up if you're a woman or a man. It's about not exposing yourself to kind of pornographic or sexually explicit, arousing literature." Well, I hadn't thought about modesty in that way. I don't think that there's anything wrong with reading sexually explicit material. I don't think it has to be a problem, but what I've learned from being here is that if it does offend their sense of not merely propriety, but what their own religion tells them to do, then it's an interesting intellectual question and ethical question how to teach important truths about the world and respect people's beliefs.

09-00:06:45

Lage:

And it has broad application in our society, such a culturally diverse society.

09-00:06:53

Asch:

So I find teaching here very challenging in a way that I didn't know, because I didn't quite know what I was getting into.

09-00:07:13

Lage:

And it wasn't discussed in the course of your hiring?

09-00:07:16

Asch:

Some of it was, but I think people didn't know everything I didn't know. We talked about what it meant to be at a Modern Orthodox institution, but I think people didn't know how little I knew about what that actually meant. I mean,

there are funny things. In Modern Orthodoxy—or in Orthodoxy—some men can't touch women, because women might be menstruating and might be unclean. So the typical American custom of extending your hand to shake hands with someone when you meet them, in fact, for many people, it's not an appropriate thing to do. Well, I didn't even know that for months. And it's actually kind of funny, because being blind, I didn't necessarily know that there are little signals that people try to give about whether they want to shake hands or not.

09-00:08:17

Lage: Of course at our age, Adrienne, we wouldn't be suspect.

09-00:08:21

Asch: But it wouldn't matter. We're still female.

09-00:08:23

Lage: It's just being female?

09-00:08:24

Asch: Right.

09-00:08:31

Lage: So how did you figure that one out?

09-00:08:32

Asch: Somebody told me. Somebody said, "Adrienne, you might want to just not extend your hand, because people don't want to shake it." I said, "Okay."

09-00:08:49

Lage: Could you teach a course on abortion like you taught at Wellesley? I don't know what the Orthodox attitude towards abortion is.

09-00:08:54

Asch: Yeah. Yeah. You can teach pretty much anything you want. You can teach whatever you want. People may or may not take it. As far as I can tell, there's total academic freedom here. You might not get anybody enrolled in your course.

09-00:09:19

Lage: So, the messages come from the students more than the administration.

09-00:09:24

Asch: Yeah, I think so. I think the administration has said—there are certain kinds of people that they wouldn't spend university money to bring. I mean, I don't think they would bring someone who said that Israel shouldn't exist as a state with university money. They might, but they probably wouldn't. You could read someone who said Israel shouldn't exist. You could assign it. You might have a mass mutiny, but you could assign it. I taught material about abortion, and stem cell research, and all kinds of things in my courses, and I taught about same-sex families. Unlike Conservative, and Reform, and

Reconstructionist Judaism, Orthodoxy doesn't support same-sex relationships. I wouldn't have a button on my door—but I wouldn't have one at Wellesley, either—I wouldn't have a gay pride button on my t-shirt, but I wouldn't have a gay pride button at Wellesley. I don't like labels and don't wear buttons. That doesn't mean I wouldn't go to a gay pride march. I'm not gay, but I would go to a gay pride march if I—I can do what I want as a private citizen, but I wouldn't—the center is called The Center for Ethics *at* Yeshiva University, not *of* Yeshiva University, because nobody wants the center speaking for the university.

09-00:11:59

Lage: I see.

09-00:12:01

Asch: And that's fine. We're not a center that takes positions as a center. Each individual staff member can have their own positions on a topic, and if I'm called by the press and asked, "What's your position on stem cell research, or abortion, or the war in Iraq?" or something, I can say whatever I want, but I have to make it clear that I'm speaking for myself. I'm not making a statement about what the administration of Yeshiva University thinks.

09-00:12:36

Lage: Would Orthodox Jews be opposed to stem cell research?

09-00:12:41

Asch: No. Not necessarily. There's no particular --

09-00:12:45

Lage: Not a Jewish law.

09-00:12:53

Asch: There are a lot of things that there's dispute about what Orthodox interpretations of Halacha [Jewish religious law] are. You might get two or three different rabbis with different views on stem cell research, abortion, or anything.

09-00:13:21

Lage: I am thinking that we're close to the end here.

09-00:13:25

Asch: Okay.

09-00:13:26

Lage: Do you have some further thoughts, or things that we haven't covered?

09-00:13:36

Asch: I guess no. Two things. The work of incorporating disability perspectives within bioethics is going on. I'm glad that I'm not the only person who's doing it. I'm one of the main people, but I'm not the only one, and I'm very glad of that. I am also very glad that sometimes I get called to talk about things other

than disability. I got called when people were talking about freezing eggs and whether that was a good idea. So I get to think about things that aren't just disability. This job is not just about disability. It's a --

09-00:14:36

Lage: It sounds like it doesn't have much to do with disability.

09-00:14:39

Asch: No. It doesn't. Although some of my research still does, and we put together a workshop on bioethics and disability, but like the job at Wellesley, it wasn't a job about disability, it was about bioethics. And this is a job about ethics. And so I can teach about disability if I want, and I can speak my mind about disability if I want, but I get to speak my mind and teach about a whole range of things. And I loved at Wellesley that I got to do a range of things, and I am here getting to do a range of things, and it's pretty clear that if people are nervous about the Center for Ethics, they're nervous about a non-Orthodox Jew running it, or maybe a woman running it, not a rabbi running it. They may be nervous about the fact that I'm blind, but that's not high on their list. The big thing on the list of people who are nervous is that I'm not Orthodox.

09-00:15:52

Lage: So it was sort of a radical act, almost, of the administration, to bring you on?

09-00:15:55

Asch: Oh, yes. Oh, yes. Oh, yes. This was a very radical act.

09-00:15:59

Lage: I can see that.

09-00:16:01

Asch: And so I'm having a lot to learn about getting along in this very new environment. But I like it. It's challenging in a good way. I'm incredibly glad that I have this job.

09-00:16:15

Lage: Do you like being back in New York?

09-00:16:16

Asch: I love being back in New York, and I am getting to do some more of other things that I wanted to do. Not as much as I'd like. I'm working very hard. Work could take over my whole life, but I'm trying not to let it.

I think that life for people with disabilities has changed a lot in some ways in the last thirty to forty years, and yet sometimes not as much as anyone would like. Fourteen years ago, I was at a bioethics summer camp—it was a kind of retreat conference event—and a bunch of us went white water rafting, and the people at the white water rafting company got very mad that I was there, and intended to go in the white water raft. I did go, but some people within bioethics there, who were my friends, sort of thought I'd gone to prove a

political point—which I hadn't. I'd just gone because I wanted to go. I didn't like that. I thought they knew me better than that.

The same person, who's a friend—I've gone to visit him and his family, I know his kids, I know his wife. They don't live in the New York area. I've gone to see them. In their home, they've had me as a guest. They've had me speak at their university. They like me. We're not just colleagues. We're friends. There was one day when we were talking about a bioethics case where somebody with a disability was denied access to reproductive technology, and the claim was made that this person, because of her disability, wouldn't be an adequate parent. And we were talking about the case, and my friend said, "Well, you know, it really would be very difficult." And I was shocked that he said that, and said, "Well, I think that there's a lot that you need to learn, and I'm kind of surprised that you would still think that, after knowing me for a long time."

But one person can't change the world, and one person can't change everybody's minds, and discrimination is subtle, and prejudice is subtle. I mean, sometimes it's overt and horrible, but getting people to change deep attitudes about ways that people are second class or not as good as they are is very, very hard work, and sometimes it comes out of the blue and hits you in the guts when you're not expecting it, when you're just going on a white water rafting trip, or having dinner. I hate that. That will never be over, as long as I live. And it will never be over for my generation of people with disabilities who have fought very hard, and it may never be over for any generation of people with disabilities. Maybe we'll always have it. When people say that, it has serious policy implications of what are we allowed to do as people: are we allowed to be full citizens and go white water rafting, or take our chances? There was one day when I walked into the same group of people, and somebody came running up to me and said, "Don't go white water rafting this trip. It's really dangerous. Somebody fell out of the boat." And I said, "Well, are you telling that to everybody else?"

09-00:20:54

Lage: So, the attitude part—it's not changing fast enough?

09-00:20:59

Asch: No.

09-00:20:59

Lage: Or maybe it's not changing?

09-00:21:00

Asch: Well, it changes for some people, and it changes for other. Other people who were there said, "Adrienne gets to sign the same informed consent that we all do, so if you want to take risks, take them." Maybe the risks I'm taking are greater than somebody else's risks, but maybe they're not. I don't like these attitudes. They're dangerous attitudes. They have consequences for whether

public policy will support our being full citizens, our being parents, our making our own decisions about how we live our lives and whether we get to end our lives the way we want, or don't. They're very serious issues. We have not won. I think we've made progress, but we have not won. I think we've got a long way to go before we win.

At the same time, I have this amazing job. I'm getting to do really fun and interesting, intellectually challenging things with a lot of great people, and my battles aren't all about reasonable accommodation, and they're not about disability. They're just the battles of any academic trying to do an unusual thing at a place with its own rigidities.

09-00:22:26

Lage: Which is really what you asked for. Do you think the legal changes that we've had, which are so important, are going to lead to those attitudinal changes?

09-00:22:46

Asch: Well, I hope so. I think race relations are better than they were forty years ago. I think sex roles are different than they were forty years ago.

09-00:23:08

Lage: And this might be a very similar thing? Racism—the kind of casual racism, and the attitudes towards women that people—even sort of good people—were willing to express forty years ago would not be expressed today.

09-00:23:25

Asch: No. Now, those things haven't changed as much in terms of disability. And the left doesn't understand about disability very much. The left isn't any better than the right. It thinks people with disabilities deserve welfare state support, but it still doesn't really get that disability is a civil rights issue and not a medical issue or a social welfare issue.

09-00:23:59

Lage: Even though it is that one category that we all might join—have a good chance of joining—at some point in our lives.

09-00:24:06

Asch: Well, but people don't get it. So there's a lot to do, and we're not at utopia. When I was eleven, I wrote a short story that I called "Perfect World," and it was about a world that had no discrimination in it. I'm waiting for that world, and I'm working for that world, and I'll never get there, but I'm going to keep working.

09-00:24:47

Lage: That's a very nice way to end our discussion.

End Audio File 9 asch_adrienne9_06-21-07.mp3

[End of Interview]