Disability Rights and Independent Living Movement Oral History Project

Diane Lipton

Parent, Special Education Advocate for the Center for Independent Living's Disability Law Resource Center, and Attorney for the Disability Rights Education and Defense Fund, 1979-2002

Interviews conducted by
Denise Jacobson
in 2001

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

Foreword

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

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Tape Guide

Interview 1: March 24, 2001

Interview 2: May 25, 2001

Interview 3: June 12, 2001

Interview 4: June 29, 2001

Interview 5: September 14, 2001

Interview 6: October 10, 2001

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Series History

by Ann Lage

Disability Rights and Independent Living Movement Oral History Project

Historical Framework

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

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

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

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

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

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

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

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

Project Design, Interviewees

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

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

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

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

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

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

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

Interview Themes and Topics

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

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

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

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

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

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

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

Project Staff and Advisors

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

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

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

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

Oral History and the Oral History Process

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

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

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

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

Print volumes can be read in the Bancroft Library and at the University of California, Los Angeles, Department of Special Collections. They are made available to other libraries and to organizations and individuals for cost of printing and binding. Many of the oral histories are supplemented by a videotaped interview session. Video and audiotapes are available at the Bancroft Library.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. The office is under the direction of Richard Cándida Smith and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley. The catalogues of the Regional Oral History Office and many oral histories on line can be accessed at http://bancroft.berkeley.edu/ROHO/.

The Bancroft Library's Disability Rights and Independent Living Movement Project, of which these oral histories are a part, was funded by field-initiated research grants in 1996 and 2000 from the National Institute on Disability and Rehabilitation Research [NIDRR], Office of Special Education and Rehabilitative Services, U.S. Department of Education. Any of the views expressed in the oral history interviews or accompanying materials are not endorsed by the sponsoring agency.

Special thanks are due to other donors to this effort over the years: Dr. Henry Bruyn, June A. Cheit, Claire Louise Englander, Raymond Lifchez, Judith Stronach, the Prytanean Society, and the Sol Waxman and Tina P. Waxman Family Foundation.

Ann Lage, Project Director
Regional Oral History Office
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Interview History—Diane Lipton

Diane Lipton was invited to participate in the Disability Rights and Independent Living Project because of her personal experience as a parent advocate of a daughter with a disability, and for her work as a well-known and highly respected legal advocate in special education for the Disability Rights Education and Defense Fund [DREDF].

Ms. Lipton's interview took place during six sessions from March 2001 to October 2001. The first session was held in the dining room of her home in Richmond, California amid a collection of family photographs, knickknacks, and books. Although Ms. Lipton's home had wheelchair access, the steep, narrow, slated path up to the ramped entrance was difficult to negotiate without assistance. Of the remaining five interviews, one session took place at the interviewer's home in North Oakland, and four occurred in the conference room at the Berkeley office of the Department of Rehabilitation, where Ms. Lipton's husband, Jim Armstrong, worked as director.

The interviewer had been acquainted with Diane for a period of over twenty years through mutual friends within the disability community. The interview sessions were occasionally interrupted by brief phone calls and visits from Diane's husband and youngest daughter, Daria, who was in the throes of preparations for her then upcoming high school senior prom. One session also includes a greeting of the interviewer's teenage son upon his arrival home from school and Diane's subsequent remarks, since she hadn't seen him for a number of years. There were also audio pauses in the tape due to Diane's bouts of chronic coughing from a rare form of lung cancer. At the time of her interview she was using portable oxygen.

Highlights of the interview include Diane's experiences of advocating, as a single mother, for her eldest daughter, Chloe, during the early years of a fledging disability rights movement, and her work as a lawyer for DREDF as she championed cases for children denied their rights to special education services in California. The interview contains an in depth discussion of the creation, amending, and application of the Individuals with Disabilities Education Act [IDEA]. Also noteworthy is Diane's personal candor regarding family issues and raising a child with a disability. She talked at length about Chloe's transition from living in her childhood home into a supported living environment. Most poignant is Diane's introspection and reflection on her own terminal illness.

Sadly, Diane died of lung cancer in August 2002. Her husband Jim Armstrong and daughter Daria Armstrong reviewed the transcript for content and clarity after it was lightly edited by the interviewer.

Denise Sherer Jacobson
Interviewer/editor
September 10, 2003
Oakland, California

I. Childhood, Adolescence, Early Years in Berkeley, Travel, Birth of Chloe, 1945-1972

Family background

[Interview 1: March 24, 2001] [Tape 1, Side A]
[1]

Jacobson: Diane, why don't we start by you telling me a little bit about where and when you were born and something about your family background?

Lipton: Okay. Let's see, I was born in 1945, I know, how old I am. I was born in New York City. I grew up in Queens and Forest Hills until I was eighteen, and then I came out to California to go to college here. My family, my parents, my mother immigrated from Poland when she was about twelve years old to escape the pogroms. Her family was very orthodox, religious Jews. She was kind of the black sheep of the family because she rejected a lot of their orthodoxy. In her late teens and early twenties, she became very involved in Left politics. Kind of Left Jewish politics, I guess, in New York.

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

My father was born in the United States. His family was from Russia. He was a lawyer. He was in practice with his brother for about fifty years. His brother, my uncle Ben, was very Left and ran on various Socialist Party tickets in local elections. I'm not sure, he may have won some. Or he was high up in some Left Socialist parties. I don't know what exactly it was, because we didn't socialize with my uncle's family too much.

And, let's see. In his practice, the things my father, he did kind of general law in the way lawyers used to do years ago. They would do closings for houses, housing, and wills, and accident cases, things like that. But his proudest achievement as a lawyer, in the fifties, they represented the Teachers Union in New York, for better working conditions and salaries and against some of the blacklisting that had gone on.

Later he represented nurses from South American and Caribbean countries who were not able to practice nursing in this country because of licensing problems. He helped work that out with the government so these people, I think it was a few thousand nurses, really, who had come here over some period of time, could work here. So he was proud of those things.

I have one brother who is five years older than me, and whom I'm very close to. He's a child psychiatrist. He works with children. He's a medical director of a clinic, working with children who have been in crises in their families, and crises, like parents who are in jail, homeless families and so forth, and teaches.

Jacobson: Where does he work?

Lipton: He works at a place called the Center for Preventive Psychology, in White Plains.

Jacobson: In New York.

Lipton: In New York, yes.

Jacobson: In a school in New York.

Lipton: Yes, he actually went to medical school at Stanford. When he was in Stanford, is one of the reasons I came to California. I went to college at UC Berkeley [University of California, Berkeley]. My parents kind of let me go that far because he was out here going to school and could keep an eye on me. He was married while he was in medical school and they had two kids while they lived out here. After he finished his internship, they moved back to New York.

Jacobson: How did your parents meet?

Lipton: How did my parents meet? They weren't very sentimental about their relationship, so there's a lot about it I don't know. I think they met, in New York, they used to have these bungalow colonies in the Catskills. You're familiar with it. They went to one of these places as a social thing with a group of Jewish Socialist leftists, or whatever. I think they met there. My mother thought my father was hilarious, because he had a very good sense of humor. They met in that environment.

Jacobson: You said that your mother was active in social politics.

Lipton: That my mother was?

Jacobson: Yes.

Lipton: She was kind of, really kind of peripherally. All of their friends were active to some degree or another. They'd hang out on the Lower East Side. I don't know. She wasn't in any leadership position or formal position. But she was active in whatever they were doing in those days.

Jacobson: Did she work?

Lipton: Later on. She was very poor when they came to the United States, and before that. She worked since she was fourteen, cleaning houses and things like that. She went to a couple of years of college, I forget, a place in New York. It will come back to me. And studied nutrition. She had a very large family of seven or eight siblings. They were poor, and she was pretty much on her own. She didn't have a lot of parental guidance or anything. Her father was in shul all the time, praying. Her mother was wheeling and dealing to somehow earn enough money to support the family.

But anyway, when my mother was married, she didn't work for many years. When I was twelve, my brother went off to college. She got a job working at Stern's Department Store in New York, Manhattan. She worked there doing clerical work for a year or two and didn't like it. Then she went to work for a travel agent in Brooklyn, a small travel agency. After a year or two, she thought, well, she could do this herself. She and a cousin of mine opened their own little travel agency in Queens. Not far from Queens College. They actually did very well. My father helped them a little with the legal parts of starting the business. She did amazingly well in this little business, which surprised her because she didn't have very much confidence that she could do something like this. But she was very intelligent and had a lot of common sense, and people liked her, and she liked people. So it worked.

She owned that travel agency, I would say, oh, God, till about two years before she died. Until she was about eighty-three. The last ten years she really didn't work in it very much. One of my uncles kind of managed it for her. It was just hard for her to really let go of that. But for many years she did well and was proud of herself that she could run this business and be successful at it.

Jacobson: What was your childhood like?

Lipton: What was my childhood like. Boy. Well, first, I have very few memories of it. Specific memories. But, well, growing up, mostly I lived in Forest Hills, from the ages of about six to eighteen, in the same apartment. In fact my parents, until they died, for fifty years, lived in that apartment.

Jacobson: What kind of neighborhood?

Lipton: It was an almost, totally, 99 percent Jewish neighborhood, which is one of the reasons my parents moved there. And because it had good public schools, and it was Jewish, and a familiar environment, and stores that had kosher this and kosher that. And Jewish food. So the kids I went—I went to public schools. The kids I went to school with were almost entirely Jewish. There were very few other kids. In high school, Forest Hills High School, the only kids I recall who were not white, Jewish kids, were, there was an orphanage across the street from the high school. Actually, this beautiful old house. I don't know if what went on inside was so beautiful, but the kids from the orphanage went to our school. Some of those kids were African American kids, mainly. But I think they were the only minority kids in the entire school.

It was a very different childhood from growing up here in California. We would play outside in the streets a lot, and go to the schoolyard and hang out at the schoolyard, and then go to the candy store to get sodas after school. It was very much out of the houses, even though the weather was cold. We just hung out outside. There were lots of kids, because there were big apartment buildings all around. School was, you know, relatively easy for me. We had very good teachers at that time, in those years. Women didn't have the options that they have now. So a lot of very intelligent and skilled people went into teaching. They got paid, you know, fairly well, and benefits. It's changed now. It was fine.

My parents' relationship was difficult. They separated a couple of times. The stress in my family was hard for me. They were often preoccupied with their own problems. So that was, I'd say, the hard part of my childhood.

Teen politics, social issues, and McCarthyism

Jacobson: What were you into?

Lipton: Well, in high school, I considered myself a beatnik. This was in the late fifties and early sixties. We used to wear black turtlenecks and black skirts and black tights. That was the uniform for me and some of my friends. That was sort of a crowd I was in with in high school. We'd walk around with books of poetry. Allen Ginsberg.

Then in high school, I also went to a Zionist camp for a few years. It was not at all religious. It was sort of the old time Socialist Zionist organization, an organization from Israel which ran this camp. That was actually, there were a lot of these kinds of camps and organizations in New York at that that time. So I went there in the summer, and then during the year I'd go to meetings. We did a lot of Israeli folk dancing and talked a lot about Israeli politics. Middle Eastern politics. So that was one thing I was into.

Another thing was, in high school there was, I guess it's an organization, a humanistic kind of organization called ethical culture. It wasn't religious, it was sort of, I don't know what it was. Philosophical humanist kind of movement. They did a lot to involve teenagers. I used to go there a lot on Friday nights, to Manhattan. We'd have all these discussions about politics and social issues. Then we'd have parties after.

So I was kind of involved in those kind of, I was involved in those activities in high school. My boyfriends, except for one, were also. That's how I met most of the few boyfriends I was very close to in high school, through those organizations. And we went on retreats. I wasn't that involved in school activities. I didn't find them that interesting, or I never really just got involved, because I had these other interests.

Jacobson: So you gravitated toward the political.

Lipton: Yes, I did. I remember in high school going to antiwar, antinuclear bomb demonstrations that SANE sponsored.

Jacobson: SANE?

Lipton: SANE was the, I don't know what it stands for, I can't remember now. SANE. It was a very big organization, at least in New York and in Europe, protesting the use of nuclear bombs. There was a very big peace movement in New York and probably out here at the time, protesting the proliferation of nuclear bombs and weapons.

— 5 —

Jacobson: Do you remember what year—?

Lipton: What year that was? I would say the late fifties. '57, '58, '59, up through, I graduated from high school in '63, I think. That was in the early sixties. 1960, up to '63. Those were the years. My parents were into those issues, too, but I don't remember them going to demonstrations. Not with me, anyway. But one thing I remember that made a very big impression on me was in the early fifties my mother had a gall bladder operation. It was the time that the McCarthy hearings were on television. She was recuperating from this operation and we watched the McCarthy hearings together. My parents were very worried about all that because they did had friends who had been pretty high up in Socialist organizations. Most of them changed when, like, a lot of Leftists in the United States, when they understood what was going on in Russia under Stalin. But I remember watching that with her.

Then I remember that the FBI was investigating my parents briefly. They had talked to the management of the apartment building we lived in, and apparently made some other inquiries about my parents. But they weren't very high profile or very high up in any of these groups so I think they kind of backed off. But I remember that from my childhood, being aware of those things. I was about eight, nine years old.

Jacobson: Were you scared?

Lipton: I was a little scared. Especially when, I think I overheard conversations about the FBI. I don't know that my parents told me directly. So it was scary. But I didn't totally understand what it meant. But it was scary.

First experiences with people with disabilities

Jacobson: I've heard that when somebody was being investigated they were often ostracized by people around them. Did you or your parents ever have that experience?

Lipton: Not to my knowledge. I'm not sure how much the neighbors knew about what was going on. If they knew, they probably would have been somewhat sympathetic to my parents. Their friends were all in the same boat. I mean, the people they really socialized with and spent a lot of time with. They remained, by the way—this group of friends, which was large. Because the friends had friends—with many of these people for their whole lives. People they met when they were in their early twenties. And some even from when my mother was a teenager, remained good friends. A big group of people. Until many of them died in the seventies and eighties. So I think their early experiences, my mother always told me that they had no money, but they had a lot of fun.

They would go to restaurants on the East Side during the Depression and during the war. They would go to restaurants where you got free pickles and bread. They would sit in these restaurants and talk for hours and hours. She always used to say that they didn't have any money but they had a good time. So those were, I think, very happy years for my parents.

— 6 —

At any rate, one other thing about my childhood that had really made an impression on me, although I didn't know how, until much later. In our apartment building there was a family who, they were Holocaust survivors. The parents. They had a son, Harry Weider. Harry was, is, I guess, I don't know the politically correct term that's used right now. He's a little person, or, what used to be called a dwarf. Very short. But his head was a normal size adult head. My parents were friends with his parents. He was about seven years younger than me, or eight years younger than me. So I used to baby-sit for him when I got older.

His father had some business in Germany and in Europe. I didn't know exactly what he was; he used to go back and forth a lot. His mother had some serious psychiatric problems that would come and go. My mother was a very good friend to her, and helped her out, because her husband was gone a lot. So Harry, I kind of grew up with him, and although we didn't have the same friends, because of the age difference, he went to the same public schools I did and was very, very bright. I don't, I've talked to him. Now he is a disabled gay activist in New York. His parents still live in the same apartment, and he has his own apartment in Manhattan. But he comes on weekends to see his parents, stay with his parents for a couple of reasons. I remained very close to Harry all these years. Whenever I'd go to New York to see my parents, I spent time with him. He used to drive me around.

Then we both wound up in disability circles. He knows a lot, he knows Pat [Wright], and he knows Judy [Heumann]. It's just so weird, kind of, that we both—but I think it was a very big influence. I was really kind of introduced to disability very early, even though it wasn't directly in my family.

Jacobson: In certain ways, he was the first disabled person that you really knew.

Lipton: Yes. Yes. Because there didn't seem to be any other disabled, certainly kids. There were older people in our neighborhood, you know, who had disabilities. But that was like, they're old. That was different. In my schools, there were none that I was aware of. There were no special classes; there were no kids in regular classes.

Jacobson: Do you remember if your schools were accessible?

Lipton: I don't think they were. My high school might have had, like a freight elevator, or something. But there was no consciousness about it. But I don't think they were accessible. So that may be why, certainly there were no kids with physical, or mobility disabilities at my school. I don't remember other kids, like kids with mental retardation who aren't physically disabled, either. I don't know where they were. They were in separate basements. I guess they were in basements with Judy and others, someplace.

Jacobson: And me.

Lipton: And you. I really don't know. It's crazy. They, you, were hidden in some basement some place. Now, Harry did go to our school, even though walking was a little bit difficult for him. Now he uses, for many years, now, he's used canes. I forget the name of them. Anyway, the kind that go around your wrist.

Jacobson: Canadian Crutches.

Lipton: Yes. I remember him wearing a brace on one leg for a while. But somehow he managed, I don't know how, because the schools were about three stories and I don't remember elevators. I can't imagine they did anything to accommodate him. Maybe they did. I don't know.

Jacobson: I better turn over the tape.

[Tape 1, Side B]

Jacobson: Tape one, side two. So we were talking about your first experience with disability. Do you have any thoughts about Harry?

Lipton: Well, one thing was, my parents were totally accepting of Harry. That influenced me, the way they related to him and to his family. They liked him; they respected him. He drove them a little crazy because when he got older he used to come to their apartment a lot, because he liked to talk to my father. They would have a lot of political discussions, and he couldn't do that as well with his father. Their attitude was very, kind of nonchalant, about his disability. They were not at all embarrassed to be seen with him, to introduce him to their friends when they were older. They used to go, occasionally they went away for the weekend with his parents and with him to some places in the Catskills. So I'm sure that influenced me, the way they related to him.

When I was a little older, when I was about thirteen, I went to this camp called Children's Colony. It was run by this woman, her name was Truda Frank, who had helped a lot of children escape from Nazi Germany. She ran this summer camp. She had this whole philosophy about education. She was kind of, she was very scary. She wore all black, and she spoke with a heavy Austrian or something accent. We'd see her coming and we'd run away. She was actually a very kind person, had saved a lot of children during the war. Well, in that camp, there's a lot of emphasis on art and theater and music, as opposed to athletics, which was some of the other camps I went to. There was one summer, and my brother was a counselor there. She used to fire him every other week.

Jacobson: Why?

Lipton: Oh, because he'd break some rule. He was the tennis counselor. And I don't know what, I'll have to ask him what terrible things he did. But he was always getting fired. Then she'd call my parents to come and pick him up. They would say, "Truda, we can't pick him up." And she'd say, "Okay, he can stay." Anyway, it was kind of amusing.

But I was about thirteen and there was a boy my age there who was blind. He was a musician. And Truda was very good friends with his parents, who were a very wealthy Jewish family. I don't know how or who they were exactly, but they lived in Manhattan in a fancy apartment in Central Park West. Their son came to the camp. Truda had put up, all around the camp—which is pretty large, many, many acres—she put up ropes around all the paths and walks of the path, so that he could get around. She went to considerable effort to have this done.

He came to camp and I was very drawn to him for some reason. Well, he was very interesting, and he was a very talented musician. I spent hours and hours talking to him.

I was very curious about his blindness. He would talk to me about it. Why he was blind, which I can't remember now. And just what it was like being blind, and how he pictured things in his mind. We just became very close friends. He wasn't really a boyfriend.

Identification with oppression

Lipton: After camp, a couple of times I went to his apartment to visit him. Then we kind of just got out of touch with each other. I'm sure he's doing something extraordinary now. But I can't remember even his name. So I wouldn't know. But that made an impression on me and, again, the way Truda handled it. He was just another kid at the camp, although she was close to a lot of the families who had some Holocaust-European connection to her. He was just there, and they did what they could to make it easy for him to get around independently.

Jacobson: I want to get back to high school. Did you work? I know that you say that you baby-sat.

Lipton: No, I didn't have any other jobs. I baby-sat. No. And neither did my friends. I don't know why, actually, we never worked. Some of my, a few of my friends, came from families [that were] pretty well off. It was interesting, in Forest Hills. There was a whole part of Forest Hills that I didn't even know about until I was much older. The part of Forest Hills where the Forest Hills stadium is, and all the tennis matches happen? That was located on the other side of Queens Boulevard from where we lived, in what was called Old Forest Hills. It had been restricted. Jews hadn't been allowed to buy houses there. It had some beautiful houses. Old houses. But Jews hadn't been allowed to live there, purchase houses there. I never even, I think I was thirty or forty before I ever drove around those streets and saw what was there, and knew that this was the same Forest Hills that I heard about on television or radio about the tennis matches there.

Jacobson: And so you were aware of prejudice at a pretty young age?

Lipton: I was aware of it, but it didn't have that much of an impact on my life, because I lived in such a Jewish environment that I didn't really feel, I felt it, I felt an identification with oppression, which I think was part of my interest in politics and social issues and civil rights stuff. Oh, I forgot to mention that was going on a lot, too, when I was in high school. But it didn't have an impact on my life directly. But I was very aware of it.

Jacobson: What kind of civil rights stuff were you—?

Lipton: Well, I remember going to civil rights marches. There was a lot going on in the late fifties, early sixties, in the South, especially. There were demonstrations and things like that going on in New York. Also, the Civil Rights Act, there was starting to be support in the late fifties, early sixties, for the Civil Rights Act, that was eventually signed, I guess, by Johnson, after Kennedy was killed. 1964.

Jacobson: Do you recall who started that legislation?

Lipton: Who sponsored the legislation? Well, Kennedy had started it and Bobby Kennedy, actually, was really pushing for it.

Jacobson: But before—?

Lipton: Before that? No, I don't. I don't know. I did know there were a lot of Jews involved in the civil rights movement. I was very aware of that. And at that time, the relations, Jewish/black relations, were different than they are now. I thought, less strained, and more working in a movement together. My uncles, my mother's brothers, owned nightclubs in Harlem. And actually, Malcolm X's autobiography, he talks about one that they owned in Harlem called the Baby Grand. They had a lot of people like Sarah Vaughan and a lot of very—people who became very popular jazz artists—performed there. They knew these people. Some of them came to the family bar mitzvahs and weddings. Nipsey Russell was another, he's a black comedian. He worked for my uncles for years. He used to come to all the family events.

I didn't understand at the time—this is, again, in the fifties, sixties, and forties, before I knew anything—but I didn't really understand that later black people would come to resent ownership of businesses in Harlem, especially by Jews. At that time, all I knew was that my uncles had this very successful nightclub there, and they seemed to be very friendly with black people. Certainly the performers who worked there, and others in the neighborhood. I think they had to pay off the police a lot. For some reason, I remember that. I kind of knew my parents wouldn't be thrilled if I married a black man, but also there was some integration of black people in our lives through my uncles. My parents never expressed a lot of prejudice. Or it was subtle.

Relationship with older brother and parents in teen years

Jacobson: You said that you were close with your brother, but he was five years older. Could you talk about your relationship with him?

Lipton: Well, we didn't, I can't remember like really playing with him or doing a lot of things with him because he was a total sports fanatic. He used to play basketball for hours and other sports, and my mother was always running after him at the schoolyards, dragging him home, because she thought he would get sick. She had a lot of weird, neurotic worries about my brother. He was truly the Jewish prince. I'd always hear about how his IQ was off the charts. He was very modest, though. He did everything he could to escape being home by playing ball with people. I remember him getting beaten up because he was kind of puny when he was in school and high school. He used to get beaten up by some of the tough kids in Jamaica [Queens, NY] or other neighborhoods he went to. His bike was always getting stolen. He was very protective with me, but we didn't have a lot in common.

But we shared a room until he went off to college. I was twelve and he was sixteen when he went to college. There was always a kind of weirdness about that. We used to, at night we would play these games that usually involved my getting punched a lot. When we'd have dinner, we would fight a lot. My mother's favorite saying was, "Meal time is hell time." Because we were always fighting or punching or something.

But basically, he was very protective. Because I would go to camps with him, and often I would be homesick for a while. He would come and stay with me and try to comfort me. He was very protective. When things were difficult between my parents, he tried to be comforting to me, too. Then he went to college and I really missed him. I was in sixth grade. He went to Brandeis. I really looked forward to his coming home and vacations. He was very proud of me. He used to talk about me to his friends a lot. They told me this later on. He wanted me to come and visit him.

Jacobson: Were you a good student?

Lipton: Was I a good student? Yes, I was a good student. School wasn't that hard for me. I did well in school without a huge effort. I did my work and I liked to read. But there were a lot of good students in my school. So it wasn't kind of unusual, or I wasn't unusual or outstanding. There were really some brilliant kids I went to school with.

Jacobson: So what happened when you graduated?

Lipton: From high school? Well, the summer that I graduated, I went with a friend of mine to Cornell. To go to summer school. Just kind of for the fun of it.

Jacobson: Upstate.

Lipton: An experience. Upstate, in Ithaca, New York. We took, I think, just one class. In modern drama or plays written in the last 200 years. It was a great experience, meeting people older than us. We had a wonderful time. Then I went to Queens College for a year. I don't exactly know why I did that. My parents really wanted me to go, to stay home and go to Queens College. I hated it. Mostly I hated living at home. I told them I had to leave. I applied to two colleges. I hated it because I was living at home. It wasn't anything like, sort of, college life. That kind of thing. Although I had some very good teachers. I think I learned more there than I did when I came to Berkeley, in some ways.

But anyway, I applied to UC Berkeley because of all the political activity that was going on out here. And my brother was here, at Stanford. I'd heard about the HUAC [House Un-American Activities Committee] stuff that was going on in San Francisco. There was a lot of civil rights activity going on at the university. I applied there and the University of Wisconsin. Anyway, I wound up coming to Berkeley. Convinced my father, mainly, that he should pay for me to go to school here.

Jacobson: The University of Wisconsin? Why there?

Lipton: Because that also was a very politically active campus. I wanted to go to a state university because I knew it would be a lot cheaper for my parents than a private college. My brother's education had cost a lot.

— 11 —

Enters University of California, Berkeley: involvement in civil rights and free speech, 1963

Jacobson: Did you have any idea at that point what you wanted to do?

Lipton: I was interested in English. Mainly because I liked to read. I didn't have any idea about what majoring in English would be like at the university. I wound up not liking it so much and being more interested in social sciences. But that was initially what I was interested in for my major. I arrived here the year before the Free Speech Movement.

Jacobson: What year?

Lipton: Well, it must have been '63, I think. I think I graduated from high school in '62. I went to Queens College for one year. Yes, so it was the fall of '63 that I came here to Berkeley. I lived in the dorm for a year, for half a year, then I moved into an apartment with friends. There was a lot of civil rights stuff going on at that time. Registering people to vote. There were a lot of students who were going down South, who had been in the Freedom Rides and activities like that. There was a lot of stuff with the *Oakland Tribune*. I forget what, I forget all the, I'd have to read some of the history here. But there was a lot of civil rights activity, which I was really interested in.

Then, the following year, the Free Speech Movement happened. I was very involved in that. I was out on Sproul Plaza every day, all day.

Jacobson: Could you talk a little bit about the Free Speech Movement?

Lipton: Well, it had to do with civil rights, and it had to do with whether, I mean, it started, initially, as far as I can remember, about whether or not students could have tables set up on campus. I don't know if it was promoting certain civil rights candidates, or promoting picketing of certain businesses around here. I know there was a lot of hostility about the car sales businesses that were supposed to be very racist. Then the businesses that were the targets of some of this put pressure on the university to not let all this political organizing happen on campus.

So the university passed some rules that you couldn't have certain kind of political activities on the campus. That provoked a huge conflict because students felt that these were their First Amendment free speech rights that the university was trying to curtail. So the students continued with the activity. So the police came on campus to arrest the students who were doing those things.

And they arrested, first, Jack Weinberg, who was a graduate student at Berkeley at the time and had been very involved in civil rights. They put him in the police car to take him away. And all the students in the area surrounded the police car and would not let the police car move. That went on for days and days. Jack was in the police car while this demonstration was happening, for several days. Mario Savio would stand up on top of the police car and make speeches in support of the students. He was a graduate student at the time. Interestingly, I think he had a son with autism, which I heard about much later. So that's what happened.

It was the first time I had seen this direct confrontation with police. It was very frightening to me. I was very scared of the police. But I stayed involved. There was one day, kind of the finale, where there was this kind of sit-in, in Sproul Hall, the administration building. I wasn't there, I can't remember where I was, but I wasn't on campus for those few hours, when the students were going in. By the time I got there, no more students could get in. Then those students wound up all being arrested and carried out and it was like the big disappointment of my life that I wasn't with them.

But I remember feeling very scared, because we'd be surrounded by these police in full police dress, with guns. They looked scary. There were a lot of Oakland police who came to help the Berkeley police and the campus police. That was kind of the beginning of real police confrontations in Berkeley, that went on for years through the civil rights movement, the antiwar movement, Vietnam, People's Park, the dispute about that. For years I was terrified of the police. I remember having to run to not get hit. But I did it anyway, because I felt strongly about it. I always figured I could, when they started to attack, I could escape. I put running shoes on.

So, my years at Berkeley were much more memorable at the university for all this political activity than my classes. My classes were kind of an intrusion on the rest of my life. I don't remember having a lot of classes that really moved me. Maybe a couple. But as an English major I had to take a lot of classes like The Complete Works of Chaucer and The Complete Works of Milton and The Complete Works of Shakespeare and 19th Century Romantic Poetry.

It seemed to have nothing to do with anything. What was happening outside was so much more interesting and dramatic. So I did okay at school. I got decent grades. I didn't get great grades, because that wasn't where most of my focus was.

Participating in changing times, marriage, and alternative teaching

[Tape 2, Side A]

Jacobson: Do you recall the beginnings of disabled students on campus.

Lipton: I graduated in '66. I don't remember any disabled students or movement happening at that time. It might have been the beginnings of something, but I don't recall it. I think it was in the early seventies, is that right?

Jacobson: Late sixties.

Lipton: Late sixties.

Jacobson: And early seventies. Do you remember any disabled students on campus?

Lipton: No. There may have been, but I don't remember seeing any, not visibly disabled students. What was happening when I left and in the next few years was the women's movement was evolving and developing around here.

Jacobson: Were you involved with that?

Lipton: Yes, I was somewhat involved in that. Actually, in my last year of college, I got married to Lenny Lipton, whom I met when I was at Cornell that summer when I graduated from high school. We'd kind of stayed in touch with each other. The summer after my junior year, I was with him the whole summer in New York. For a variety of reasons I won't go into, I mean, they aren't that relevant, we decided to get married. We got married in New York at the end of the summer before my senior year. Lenny wanted to move out here.

Jacobson: What year was that?

Lipton: I got married in 1965. Early September, 1965. And he had graduated from Cornell and was working for photography magazines as a writer. So he was going to be able to do his work out here. He also wrote the lyrics to the song "Puff the Magic Dragon," with Peter Yarrow, when they were at Cornell. That song was popular then. So he was getting royalties from the song and writing for these photography magazines. So he came back here with me and I finished my last year at Berkeley. For that year and the next few years, we were very good friends, close friends, with the publisher of what was called the *Berkeley Barb*. It was one of the first alternative newspapers in the independent, sort of alternative, newspapers in the country, with the largest circulation, as it had. He wrote for the *Barb* and through that we became friends with some of the leaders of the political movements going on here, and the antiwar and women's movements.

Jacobson: Like?

Lipton: Like Stew Alpert, the guy who started the magazine, Robert Sheer, who else...well, Max Sheer, it's a different Sheer. Max Sheer who owned the *Barb* and was the publisher of it. Jerry Rubin, we knew through Stew, but not well. Let's see, who else was here at the time. There were others. I'm just blanking on people's names. But at any rate, we knew some of them really well. Like Stew, who was one of the big leaders of People's Park. There were others, though.

Anyway, I went to a women's group with the girlfriends of these male leaders. They were all talking about how they were treated as second-class citizens and relegated to making the food and doing this and that. They were very angry about it. There were also women in Berkeley, there was a small group of women in Berkeley at the time were learning how to use guns. Just in case the revolution came quicker than we thought. I didn't do it because it was too far-out for me. But women in this group were going to target practice. Many of them had never seen a gun, let alone, nothing much came of that in terms of anyone using guns, but it was an interesting short period in the movement.

Jacobson: Did you also work for the Berkeley *Barb* ?

Lipton: Did I? I wrote a few articles for it. But Lenny wrote a regular column on film reviews, and related other, whatever was happening at Berkeley at the time.

Jacobson: What kinds of things did you write?

Lipton: I think I wrote things more about women's issues. The few articles that I wrote. I think I wrote one about People's Park. Not a lot, but I did write some that were published in the paper on those things. Then, after I graduated, Lenny and I went to Europe for a year and traveled around Europe and North Africa, and then came back, and I got a teaching credential. I had various jobs working at child care centers, bookstores, and after a year or two of that, decided to go back to school and got a teaching credential at San Francisco State. And was doing my student teaching in an alternative school that Berkeley High School created.

That was the era of alternative schools. They created one within the public high school. I'm very close friends now with people whom I was in that program with. There were about ten of us working in this alternative program, getting our credentials. In fact, a few of the people we were out of touch with for a while, we just got together with. But two of the women in that program have been very close friends of mine ever since.

Jacobson: When you say alternative school, could you describe it?

Lipton: Well, there was Summer Hills. There was this movement in education to really look at the way kids were being taught and what they were being taught. An emphasis on promoting the individual abilities of students and teaching, and also the idea of small classes, more discussion, more focus on sort of student-centered needs. More classes that were relevant to students. More freedom, more creativity and so forth. I think some of it was a backlash to the big emphasis on science and math that came out of the Sputnik era. So there were alternative private schools. They were called alternative schools. They often didn't use grades. They would work on big projects rather than small book assignments. Very much hands on, things like that.

So Berkeley High School decided to try to create one of these little schools within Berkeley High School. We had classes like Poetry in Rock Music. I taught that one. We had one in the Russian Revolution. I taught that one also. The only thing I knew about the Russian Revolution was I'd read a little bit of Lenin, and I'd read Trotsky's book. I was like a chapter ahead of the kids. So they had kind of real offbeat classes. The kids who were attracted to it, there were maybe fifty, seventy-five students, in this program there, tended to be kind of offbeat, interesting students. I actually became friends with a couple and stayed in touch with them for many years. We weren't much older than some of them.

Jacobson: How long did you teach?

Lipton: I taught just that one year. Then some of the people I was teaching with, the other student teachers, we got our credentials. They started a private school called The Daily Planet. The stories about that are hilarious. But I didn't do it with them, although I remained very close to them, because I was pregnant. I was pregnant with Chloe.

Jacobson: This is a good point to stop.

II. Chloe's Disability, Early Education, Initial Contact with CIL [Center for Independent Living], 1972-1977

Events preceding Chloe's birth

[Interview 2: May 25, 2001] [Tape 3, Side A]

Jacobson: We left off last time when you were about to talk about Chloe and having kids. And I realize that when we talked about your parents, you never mentioned their names.

Lipton: Their names? Oh.

Jacobson: Yes. So for the record, could you tell me their names?

Lipton: Yes. My mother's name was Rachel Zelman, and my father, Irving Zelman.

Jacobson: And your brother?

Lipton: Arthur Zelman.

Jacobson: And you were married to Lenny Lipton. When did you get married?

Lipton: Let's see. I think it was 1965, when I was twenty, we got married.

Jacobson: Tell me about you deciding to have children.

Lipton: Let's see. The first year after we were married, we traveled in Europe. No, it was right before my last year of college. So I finished college here at Berkeley. And Lenny had already finished school and was doing writing for a couple of photography magazines. Anyway, we went to Europe for almost a year in North Africa, traveled. Then when we came back, I had various jobs, working in a child care center, bookstore, then we spent a summer up in Oregon, near Eugene, in a satellite house we rented with some friends. A satellite of Ken Kesey's house in the country. And that was in the time when people were traveling around in buses around the country, young people, and so busloads of people would arrive at Kesey's farm. He lived up there. And they would send the overflow to this house we were renting with some friends.

Jacobson: Was this like people in the civil rights movement or hippies?

Lipton: They were hippies, more of a hippie ilk, I would say. But they were also somewhat political. They weren't total flower children hippies. Just like Kesey wasn't. He was kind of, he was very politically aware of things and involved to a large degree. So the people who were there were kind of a mixture.

Jacobson: And they were involved in the Free Speech Movement?

Lipton: Not these people. These people were more, they were from different parts of the country. They were not necessarily from Berkeley. And we just met people. I mean, strangers would come to the door and wind up coming in for coffee and staying for three weeks. So we had a bank robber who stayed there, who was on the lam, I guess you could say. We had all kinds of interesting people. It was wonderful, really. It was a lot of fun. There were drugs. Not everyone was hugely into it, but some were. And all kinds of other experimentation.

We spent three months there in that old, beautiful house. Run down but beautiful house, out in the country. It was a difficult time, too, because it seemed like there were no rules for anything. Because of that, things were very intense. Everything was intense. From deciding what to cook for dinner, to people's marital relationships. Everything was sort of up for grabs. But it was a very warm, supportive group of people, basically. Then we came back to the Bay Area and lived in El Cerrito. People from Oregon would come and visit, and we'd go back up there and visit people we knew who lived there. So there was a lot of migration up and down from the Bay Area to Oregon.

Jacobson: What year did you live in Oregon?

Lipton: It must have been around 1970, 1971. Sevnty, I think, because when I came back, I decided I needed to do something real as far as jobs went. So I went into a program at San Francisco State University to get my teaching credential. I got the teaching credential in secondary education. That was an interesting year, too, because that was a period of time when alternative schools were popular. So Berkeley High School created some small schools within the big schools. Which now, thirty years later, they're doing again.

So our program, I student taught. I didn't really student teach, because nobody supervised me, for that whole year, and became very, very close friends with other people who were doing the same thing. I'm still very close with some of those people. It was kind of wild. We taught classes like, I taught a class in history on Trotsky. Not that I knew that much. I read one book, so I knew more than the students. It was very alternative, and we had classes like Poetry and Rock Music was an English class. A lot of art classes and music. I don't know what the students, looking back, thought was going on there. But it was very, very alternative. There were a lot of interesting students in it, actually.

So I did that for a year, got my teaching credential, and then, it was that year that Lenny and I thought seriously about having children. I guess it was toward the end of that year, summer, that I got pregnant. I don't know how much I talked about Chloe's birth and all that.

Chloe's birth: one of triplets, 1972

Jacobson: We never touched that. And this was '72?

Lipton: This was, I must have been pregnant in the fall of '71, because Chloe was born in '72. And let's see, when I was about two, well, three months pregnant, they suspected that I might be having twins. But at that time, they didn't really have ultrasound. This was thirty years ago, almost. And they didn't like to take x-rays early in pregnancy. So they were just sort of waiting to see how things developed. Then when I was about six months pregnant, I think they did do an x-ray, or they were just beginning to use ultrasound. I can't remember exactly which. But anyway, they discovered that I was having triplets, which was pretty strange, because there were no multiple births on either side of our families, and no apparent reasons, like fertility drugs I had been taking or anything, why I would have had triplets.

But at any rate, they told me I was pregnant with triplets, which was pretty shocking. I just couldn't imagine. It was overwhelming and upsetting, very upsetting, because it was just unimaginable how this happened and how we were going to handle it, and so forth.

Anyway, to make a long story short, I went into labor early, which was pretty usual. I probably should have been in the hospital before that, but anyway, that's another story. So at seven months, maybe it was twenty-eight, twenty-nine weeks, or thirty weeks, maybe thirty weeks, I went into labor. I was in the hospital. They tried to stop it, but within a few days I went into real labor and delivered. I had three girls. One of them was stillborn, which is why they thought I went into labor. And one other baby lived for a day and a half, and then Chloe was the third baby.

I never saw the one that was stillborn. Things have changed a lot since then. They were much more into, sort of, the idea of protecting you from becoming attached, or, I don't know what they thought they were protecting you from, but anyway, we went through a very painful, difficult time. The one baby that died after a day and a half, she developed respiratory problems. Her lungs were just too underdeveloped. The technology then was way different from how it is now. Much less sophisticated. They probably would have done much better now. Chloe and the other baby.

Chloe's early development, diagnosis of cerebral palsy, finding resources

Jacobson: Where was this?

Lipton: This was at Kaiser in San Francisco. Then, with Chloe, it was really touch and go for a few weeks. She was never on a respirator, she seemed to be breathing okay. But there are a lot of other things that can cause brain damage when they're that little and fragile. At any rate, she had a lot of the usual difficulties premature babies have. They have difficulty digesting food, getting their digestive system working, her liver was immature, she was very, just immature. As I said, they weren't as sophisticated as they are now in how to treat some of these things. So it took her a long time to start gaining weight, and a long time before I could hold her outside of an incubator. We would spend a lot of the day, every day, at the hospital. Eventually she started to gain weight and eat well and seemed to be doing fine, eventually, after two months, and we took her home.

Very little was said to us about the actual risks of prematurity and the fact that she may have brain damage. They did tell us that her development for a while might be slower than a full-term baby, but that eventually she would catch up. There was really very little more said than that. So we took her home, and she seemed to be, she was eating well, and doing well. She started to kind of smile and respond. They said to consider that she was born around the time developmentally, around the time we took her home, that the two months in the hospital were like the two months she would have been in the uterus in terms of development. So it seemed like there were certain things she was doing at a kind of normal pace, whatever that is, like smiling when we would have expected to, and being very responsive.

Anyway, by the time she was about ten months old, I started to get suspicious that there was some problem, because she wasn't, I had no other children, and I didn't have anything to compare her development to, but I was reading books and knew that at three months, babies do this, at six months, that, and so forth. And she wasn't doing those things. And she had very poor head control. The doctors, when I'd raise this, they would sort of pooh-pooh my concerns. Just say, "She's very little and needs time to catch up." I felt that something else was going on, just by her tone, the way she felt when you'd hold her, and her head control was not good. I just knew that it was not what they were saying. And I know many other parents have had that same experience, of being pretty certain that something was going on, more than what the doctors were either admitting or sensing.

So when she was a little under a year, we took her to a neurologist, which was a horrible experience. This was a neurologist at Kaiser. I went to the appointment by myself and saw the neurologist. This doctor came in, sat down, actually, he didn't sit down. He stood over us. I was holding Chloe. And in a, literally within a second, he said, "She's got cerebral palsy and she may never walk. And it's hard to tell her intelligence at this point. And that's about all I can say right now, all we can really tell. And, you know, come back in six months or something." And he walked out. That was literally the entire encounter with a doctor.

I was just completely blown away. Chloe started crying. I called a friend of mine who lived in San Francisco because we still lived in El Cerrito. I asked her to come and give me a ride home. I didn't think I could drive, I was so shaken.

I went home and gave Lenny the news. It was just totally devastating, because I had no idea. I didn't know what cerebral palsy was. I don't know if he assumed I knew what I

knew. I didn't know what to do with her, or how to help her, anything. It's a shock to find out that you sort of have to totally readjust your fantasy of your child and change your expectations, your everything. But I didn't know what to change them to. I never knew anyone with cerebral palsy. So I was just completely clueless.

Jacobson: He never told you what to do or where to go?

Lipton: He told me nothing. Nor did he say he'd have a social worker call me, or, nothing. Absolutely nothing. And I know, again, other parents of Chloe's generation have had very similar, same kinds of experiences. Because I'd never been exposed much to disability, I just really had no idea what this meant in terms of her life, our life, anything. It was quite devastating news. So what is kind of typical for me is when I feel overwhelmed, and things are out of my control, the way I cope with those kinds of feelings and situations is sort of to get into action, to do what I can. To do something. So I made some calls and found out that Easter Seals in Oakland, they had some physical therapy.

Jacobson: How did you know who to call?

Lipton: You know, I'm really not sure if I just looked in the phone book. No one called me to say here's some resources. That didn't happen. I really don't know how I got to Easter Seals. It may really have been just looking in the phone book, because I'd heard of that. Also, I'd heard of United Cerebral Palsy because ironically, when I was a kid, my mother and my aunt, used to sell raffle tickets in New York. You remember?

Jacobson: My mother did, too.

Lipton: Did the same thing? They used to always sell, every year, raffle tickets, and go to this big fancy luncheon in Manhattan or something. A couple times I went with my mother and my aunt.

Jacobson: And they used to hold it at the Waldorf [Astoria Hotel].

Lipton: Right. It was like a big social event. There were people with CP there. I remember them sort of being dragged across a stage. These cute little crippled kids or something. But it didn't have that much impact on me at the time. I used to wind up having to sell those tickets for my mother, to neighbors. So I guess I knew the name of an organization. So I think that really, literally, I looked in the phone book. Maybe I called United Cerebral Palsy and asked them, and somehow got to Easter Seals, and went there because they said they did provide physical therapy. That kind of led me to one or two other resources.

Until, when Chloe was about a year and a half, I discovered, that about five minutes from my house there was this whole center run by the county mental health, for people with severe disabilities. And there was an intensive care nursery program. Or not an intensive care, like an early intervention. They didn't call it that at the time. Nursery school kind of program. They took kids from birth on. So I called them. Somebody, I don't know, again, definitely no one connected with Kaiser. They didn't know anything, or tell me anything. This was the days before the regional center. There were no regional centers yet. Almost, then, but not quite yet. I discovered this whole resource five minutes from my house. But that was like eight months after Chloe had been diagnosed.

She started to go there for physical therapy, outpatient physical therapy. Then, within a couple of months, they had room in their baby program. This place was called George Miller West Development Center, because George Miller, Congressman Miller's father, had been instrumental in starting these centers. And for their time, they were very progressive. It was all disabled kids and babies. It went from birth to adult. They had different classrooms for different age groups.

Emotional support from friends and family

Jacobson: What kind of support did you get from your friends and family?

Lipton: Well, my friends were great. I did not experience what some parents experience of being isolated from their friends, not knowing how to deal with it, and kind of disappearing. My friends, maybe because I had friends who were hippies and freaky and leftists, they were not turned off by it. They were used to dealing with people who are different. It didn't frighten them. So my friends, our friends, were great, and very, very supportive.

My family also was, although they lived far away. My whole family was on the East Coast, and so was Lenny's family. He had only a mother. His father had died, and he had no siblings. So we had no family close by to help us. I remember us having to tell my parents about the diagnosis, and dreading telling them. I just thought they would be so upset and worried and freaked out. Because I grew up in an environment where you didn't discuss illness, certainly not with children. You didn't talk about death. And you didn't really talk about disability. If somebody had a disability, you'd never refer to it directly or openly. Always, these issues were very anxiety provoking to my parents and their generation. Kids were supposed to be protected from all that.

We know now that that's not a sensible way to raise children. So their squeamishness about all of those things made it very difficult for me to tell them that Chloe had cerebral palsy and that she may never walk, and that we weren't sure about her cognitive development, and so forth.

When I finally was able to tell them, and I remember sort of telling it to them in little pieces, they were actually fine in the sense that they loved her very much; they were very supportive. But I know it was painful for them. They didn't say that. They were not wanting to add to my worries. But they were always very, very loving with Chloe and totally accepting. But, again, they didn't live here and they weren't able to actually help us. Our friends weren't really, either, because they were all very busy in their own lives. We were all pretty young, we were like twenty-five, twenty-six. It was a good thing I was that age, because I needed a lot of energy.

So the whole thing has the feeling of being just some terrible tragedy that happened to us. Even though people didn't act that way, so much, around us, our friends and family.

That's how I perceived it. That's how I felt, particularly with respect to my family, that this terrible thing had happened. Just in general, how I felt, going out with Chloe. It was like I was going out with this—[interrupted by phone]

[Tape 3, Side B]

Jacobson: Interview Two, Side B.

Lipton: Where was I? About the tragedy—

Jacobson: Is that how you felt or how you thought other people perceived it?

Lipton: Well, it's definitely how I thought other people perceived it. I'm sure there was some part of me that felt that way, too. Although I didn't, when I was with Chloe, I didn't experience her that way. She was just my kid. You know, enjoyed her and took care of her and loved her. I didn't look at her and think, "Boy, you're a big tragedy, a mess." But I think it was more the situation that felt like a tragedy to me. Because I had no idea. It was like sort of being blindfolded in a bad dream or something. Not being able to see a future. In that respect it seemed like hugely difficult impact. Huge, hard impact on my life. Because I just couldn't imagine, I didn't know what to imagine was in store for her, for us.

It was difficult even going out. People would always stare, especially as she got a little bit older. Or ask stupid questions. More than that, though, I started to get very aware of what other kids her age were doing and she wasn't doing. If I felt depressed and sad and tragic, it was with respect to that. I found it very hard to be around kids who weren't disabled. Because I could see, then, what she wasn't able to do.

But she didn't seem miserable. Her reality was her reality. She would smile and laugh. She's very social, always. She didn't have any perception of herself like that. I mean, I don't know what babies would think, anyway. But she didn't seem depressed or withdrawn or in any physical discomfort or anything like that. So there was this kind of contrast between her as a person and the way everyone else perceived the situation. And me, including me, to some extent.

I felt like I totally disappointed my parents. They never said things to make me feel that way. This is really a projection. Maybe they did feel that way, but they certainly never communicated that. They always enjoyed her, and were proud of every little thing she could do. But I know it was very hard for them. Then, one thing that helped a lot, was, when Chloe started to go to this nursery program—[tape cuts off, resumes]

The George Miller Center: the unifying factor of disability

Jacobson: You were starting to talk about what was helpful to you during that period.

Lipton: Well, when Chloe, I guess when she was about a year, or fourteen months, around then, we started to take her to this George Miller Center—and it was also called Hilltop because it was on Hilltop Drive in Richmond—for physical therapy. That was a very positive experience. Two months later, they had a space in their nursery program. What was so good about that was that they loved the babies and the little kids. They were so positive, the staff there. They thought everything they did was so cute, and they were so cheerful and positive that it was very good to be around that. They really wanted parents to come and hang out and be there as much as possible. Some parents could, some couldn't. But if you could, they really liked having you around.

But it was, the woman who ran it, her name was Lois [Raimis?], she was a nurse. She was just terrific. She really ran that program so well, with the aids helping. They were busy all the time. For a lot of kids, napping there was hard. And within two days she got the kids kind of, I don't know how she did it, into the schedule of the program. Again, the main thing was, they were so positive about the kids. Any little thing they did was like a big deal. So that was really a very, very good experience.When Chloe went into the nursery, she was almost two years old, or about two, somewhere around there. They started to potty train the kids. It never occurred to me how to even do this, or if she could, or, you know, and they just had this whole routine. She's two years old, this is when we start doing this. They had a potty seat, and they adapted everything so she could sit well. They just started to do things that you would do with kids who weren't disabled—working on her eating by herself, and they developed cognitive kinds of stuff. It was a very intensive, excellent program. Today we might say, we might think it was too segregated.

At the same time, I met other parents, who I had never met, up until then, of kids with disabilities, and which, to this day, we're still good friends. Like Pam Steneberg. Pam's daughter was in that program. That's how I met Pam, almost thirty years ago. And another friend of ours, another Pam, her daughter is still friends with Chloe. Her daughter has Down's [Syndrome], and she was in that class. So a lot of kids, actually, I still know from there.

Jacobson: What's her name?

Lipton: Carla Mirabella is the girl's name. There are other kids we still actually know from that program whose families still live around here and have been in Chloe's adult program. Also, the parents had kind of a support group. I met people who were totally different from me. I was making Jello molds for the parents' meeting. I'd never made a Jello mold before. The parents were not like, didn't have the same background or experiences I did. A lot of them just seemed much straighter, more traditional or conventional, but there was this connection about our kids that really transcended those differences in a very deep way which was why people who were very different in terms of economics, race, educational background, everything, really became very close, because there was this connection that transcended those kinds of differences. That's still true. I find that always to be true, wherever—

Jacobson: Disability is a unifying factor.

Lipton: Yes. It is a unifying factor, and it's something that has such a big impact on families that to find another family that's dealing with those same issues, everything else sort of fades away in terms of, not totally, but largely, in terms of helping each other and understanding each other and what each other is dealing with. A lot of the parents had families who had rejected them. I don't know if it happens as much. I mean literally, just wouldn't have anything to do with them because they had a child with a disability or they got very weird and distant. So some of them were dealing with some family and personal issues. And then the stresses on marriages when you have a child who requires a lot of intensive attention and stress and, so, people were affected in many different ways. So it was, really, a very unifying experience. A very powerful connection that parents had with each other. Even now, I could go to a conference on education and meet another parent with a kid with significant disabilities and there's an immediate kind of connection and understanding between us.

Regional Center services, medical treatment, and therapy program

Jacobson: Let me ask you about Chloe's therapy. What did they tell you about—

Lipton: Like her physical therapy?

Jacobson: Yes.

Lipton: First of all, by this time, by the time she was about two, we'd already been to several doctors. Everyone we went to said something else.

Jacobson: What kind of doctors?

Lipton: A couple of neurologists, an orthopedist. We went and saw some team of people at UCSF. Oh, by that time, the regional center system had just begun. And they—

Jacobson: That was '73?

Lipton: '73, '74. It started in San Francisco. At that time, it was teeny, and they would call you, to see if they can help you. That's totally changed now. But anyway, they referred us and paid for us to go to UCSF. Kind of to get a second opinion and to have this multidisciplinary team of doctors sort of do an evaluation, I guess. That was a pretty bad experience, too, because I remember we went there, and we weren't familiar with the place or the doctors there. We were waiting in an examining room and we put Chloe on the floor on a blanket to play, because we were waiting for a long time. The doctor came in and stood above her and kind of kept, whenever he referred to her, he'd sort of point to her with his foot, almost like she was some object on the floor. It was really awful.

Everyone we saw at that time, some said she'd walk by the time she was three or, you know, by the time she was five. Some said she'd never walk. After a few of these experiences, we realized they didn't know what the hell they were talking about. We started to have a whole different relationship with the medical community. We realized they don't know, they don't know what to do, and we're really in charge of what should happen, which is kind of scary, because it's nice if you can feel like you can rely on experts. But at sometime pretty early on, you realize that these people, they just don't know; they're more hung up about disability than you are.

— 24 —

But the therapy was basically, I think it was based on the Bobath [Method]. Bobath was a woman who developed this sort of developmental approach. It did a lot of things like to try to help her establish equilibrium, and rolling on balls and bolsters. It was kind of, I don't know, I think their goal was to sort of facilitate more normal developmental development. Or physical development. Also to sort of do what we call sensory motor integration stuff now, and to have her experience, actually crawling and sitting and things like that, to give her that kind of input. We just did it. I don't know that we ever really, I mean, it seemed like a good thing to do. I don't know how much it helped. I think it helped at least in the respect that it kept her loose and moving and maybe did give her some input she might not have had for her brain. Some of it she liked, some of it she hated. It was kind of, really, who was doing it that she responded to. If she liked the person, it was fun. If she didn't, she hated it. We would do it at home every day. We had this whole routine.

Then she was getting speech therapy and OT and a million therapies. At the place where she was at, it was very multidisciplinary. I mean, they all worked together, which never happened after that. She left there, as well. There was another weird aspect to that place and that was the psychologist. They would have these meetings with parents and all the experts, like, I don't know, once a year or something. Those meetings were torture. Parents would dread those meetings.

Jacobson: Why?

Lipton: Because they would have some psychologist who everybody thought was weird himself, and he would sort of make these pronouncements about how smart the kids were or weren't, in a very cold way. He was very cold. He'd come to these meetings and there would be like fifteen people there and you. I can't tell you how I dreaded those meetings. You would sit there and they would all go around and give a report. It was a very unreal experience. You'd sit there and wonder, "Are they talking about Chloe?" Because it would sound like they were talking about someone you didn't even know. They really didn't ask for the parents' input, particularly. You just would sit and hear this. He would sort of make guesses about IQs, the psychologist.

I don't think the teachers liked it very much, either. I always remember them seeming uncomfortable with the whole process. Parents used to dread going into those. Because it always seemed like they were going to tell you bad things. All the things your kid couldn't do.

At any rate, mostly, though, being there was very good and positive. And showed us things to do at home, like the potty training. Like how to help her eat, and what kind of cups would be easier for her, and spoons. And how to position her at home in a wheel—not in a wheelchair, she didn't have one then—but in a high chair so she could sit well and she was comfortable.

Also just what kind of games and toys would be good for her and things like that.

Jacobson: Were you working at the—

Lipton: No. I wasn't working at the time.

— 25 —

Cameron School for Orthopedically Handicapped: beginning of advocacy, 1975

Jacobson: You were a full-time mom?

Lipton: Yes, I was, which was good because I had the time to spend up there. The only time they made me leave was when it was naptime because they said she wouldn't go to sleep if I was around. So they told me to go take a walk when it was time for naps and stuff. But they were right. But I spent a lot of time there and I learned a lot from them. Some of them, like Lois, who was the head of it, had many years of experience. And then, you know, I met other parents. Those were the days when a lot of young mothers didn't work as much as they do now. So that was fortunate I didn't have to work at that time.

Jacobson: How long did she go there?

Lipton: Well, the nursery program she was in went up to age three. At age three, that was another big sort of traumatic event, because when the kids turned three, they would make a decision about what was going to happen next. In Richmond at that time, they had a school for what they used to call TMR, trainable mentally retarded, that was run by the county. The school district ran a school for orthopedically handicapped kids. It was called Cameron School. There was one other school. Or you could stay at the development center if they thought you were more severely retarded.

So there were these three options. And they just decided. This was before [Public Law] 94-142, IDEA [Individuals with Disabilities Education Act]. Or actually, it was about the same time. She was three the year the law was passed. But we didn't know that for a while. It was a well-kept secret. Anyway, they said that, they referred Chloe to the school for orthopedically handicapped kids. There were many kids at that school—it went from age three to high school—who had no mental retardation, and were only physically disabled. Actually, the older kids started to get a little bit integrated into the high school, but they were way behind academically because they just hadn't had a good education there. As good as they should have had.

And then there were kids like Chloe. She has physical disabilities, and some cognitive disabilities. Some degree of mental retardation. But not enough so that they kept her in the severely retarded program. So I was actually really pleased that she was sent to this orthopedically handicapped school—it's also very close to our house—because I thought she would get the most stimulation there.

That turned out to be the beginning of my real advocacy efforts, when she started to go to that school. It was started the first day. Actually, the school districts in the county were bussing the kids to and from these programs, which I thought was amazing then. Actually provided transportation. But the first day of school at Cameron, I brought her to school because it was a new experience for her. But I was carrying her into the building and the principal met us at the door and she said to me, you know, "If your daughter can't cut it here, she's going to have to go back to the development center." And I was like, "Whoa." I didn't know why she said that to me, and it seemed like the most unwelcoming thing to say to a new child and parent. She didn't really know if Chloe could understand what she was saying or not. But I certainly did, and she knew I did. That was very, very, very upsetting. I got on a bad footing with that principal from day one.

Jacobson: What did you say in return?

Lipton: I said, "What do you mean?" I didn't understand. She said, "Well, this may not be the right place for her." It was like she was talking about Harvard or something. And, you know, "If not, we'll have to look at something else." I was like, "Oh, boy, where do you come from?" Then Chloe went in; she was in the nursery pre-kindergarten, because she was only three. She had a wonderful teacher there. The program was actually really good for the younger kids, as a segregated program goes. I mean, they got a lot of attention. It was stimulating.

However, it was on the same block as a regular elementary school. It was the same block, and the schools were divided by a fence, and there was never any contact between the disabled kids and the nondisabled kids at the regular school. Except at Halloween.

At Halloween, they allowed—and both of the schools are run by the school district—they allowed the kids from the handicapped school, in their costumes, to parade, there was a parade around the block of the regular school. They would let handicapped kids in their costumes walk at the end of the parade. But that was like once a year on Halloween. I just thought maybe, because they're all wearing costumes, everyone looks freaky anyway. Other than that, there was no contact.

Jacobson: What did you think about that at the time?

Lipton: Well, at first I think I felt grateful that there was a school there for her at all. It didn't really occur to me until she was about five or six years old. I didn't really question this separation until she was about five or six. But between three and five, we had a number of other problems with the school and we started doing advocacy. Like the school day was shorter for our kids then the district-run program for three- to five year olds. Regular kids. Actually, it was up to age seven or eight that the school day was shorter for the disabled kids. That didn't make any sense to us, because they seemed to us, they needed more help, not less help. And so that was—

Jacobson: Did they give you a reason for that?

Lipton: No. Because this was really, I'm trying to think, this was right when the federal law was passed in '75. There weren't regulations for it until '77. I think the school district, at that time, didn't think there was anything they were supposed to be doing. So their attitude was that we should be grateful for what they are providing, and they're doing the best they can. That was totally their attitude. And myself and a couple of the other parents had some feeling that this was some kind of discrimination because why should the kids get a different school day as everyone else. But we didn't know about the law.

We did go to Sacramento, actually, not having a clue what we were doing. We just thought, this is not right. Also the principal was a very difficult, unpleasant person, and no one liked her. There were other kinds of issues, but that was one of the big ones. So, immediately I became kind of a troublemaker at the school. With Pam Steneberg, whose daughter went there, too, and a couple of the other parents. We got into arguments with the principal all the time.

We'd go to Sacramento and ask, we didn't even, I don't know how we even knew who to call or meet with, but we would go and find someone in the Department of Education, and talk to them. Some of the things changed, actually, as a result of that. But it wasn't until Chloe, as I said, was about five or six years old, that I started to question the—oh, I know. When she was about five and six, I did start to question why the kids never had any contact with the nondisabled kids. I met, through DLRC, I guess maybe she was a little older, seven or eight then. Pam and I went to CIL [Center for Independent Living], because we thought we could get some help with some of our little issues at the school.

Jacobson: How did you know?

Lipton: I have no idea how I knew about CIL. Maybe I just, I used to go to Telegraph a lot, maybe I just saw it there. I really don't know how I knew about it. But we called there and we said we had disabled kids. I think maybe we'd heard something about a law, but nobody told us anything about it. And we asked for help with the school, because it seemed like there were a lot of problems. DLRC, the Disability [Law] Resource Center, kind of was the legal arm of CIL at the time.

Jacobson: Hold that thought. I've got to turn the tape over.

Connects with CIL, receives training in P.L. 94-142, 1977

[Tape 4, Side A]

Jacobson: You called up CIL.

Lipton: Actually, what I think happened was somehow Pam and I heard that there was a training. There was a new law, and there was a training in this law. Not by CIL. By this woman Marie [McKeifer?] who was a big parent advocate at that time. Pam and I went to this training; it was a one day training. We were just totally blown away.

Jacobson: Where was it?

Lipton: It was in—I think Marie came—it was someplace around here in Berkeley or El Cerrito. We'd seen some flyer or something. That was like a real turning point because Marie actually had been involved to some degree with some of the drafting of the law. She really understood it and knew it. There probably were about fifteen or twenty parents there. It was an all-day training. We were just completely amazed by it, that our kids had all these rights, and IEPs [Individual Education Plans], and you know, the whole thing. Rights to all these services if they needed them, and the least restrictive environment part. Although Marie wasn't into that law and never was, which is sort of why a lot of parents had a parting of ways with her years later.

But at any rate, the biggest message that she gave parents at that training was that there was this law with all these very detailed protections, and that we, as parents, were the experts on our kids. It was very empowering. That was her message. Not to be intimidated by these professionals. Not to think that they know more than us about our children. It was very powerful. She was a very good trainer, and speaker, and a parent herself. So that changed everything, because we didn't have to be grateful anymore for their little program. Our kids had rights; parents had rights. Parent participation was a very critical part of the law. And for a reason. Because the law respected that parents knew their kids, too.

Jacobson: Do you remember what year that was?

Lipton: I think it must have been at least '77. Because I think the regulations were already out for, it was called P.L. 94-142 at the time. So it was at least '77. Maybe '78 or '79.

Jacobson: Okay, because I have a note here from Mary Lou Breslin, and she said that she met you in '75 or '76.

Lipton: I think it was later. I think it was later because I met Mary Lou at the DLRC [Disability Law Resource Center]. I don't know when the DLRC was started. I don't know if it was as early as '75 or '76. I don't think it was.

Jacobson: No, I think it was later, too.

Lipton: I think it was in the late seventies. '78, '79. So we went to this training. We learned that there was this law. From this law we knew that they weren't doing things the way they were supposed to at the school. That was very clear to us. The law was in effect and our kids didn't have IEPs, and things were not happening. They would cut services based on the schedules of the therapists, which you're not supposed to do. A lot of things were happening that did not jive with the law. So that's when we called CIL. Again, I don't know how we knew about it. Oh, I do remember, maybe becoming aware of it in '77. Seeing the 504 sit-ins on TV. And kind of becoming a little aware that there was this disability movement happening. I saw the sit-in at the federal building on television.

Anyway, I don't really know, but maybe, again, because I passed it on Telegraph. So we went there and DLRC had started then or a year before or something. There were two people there. Arlene Mayerson, who was an attorney there, and a parent advocate, Julie Landau, who was this twenty-two year old, very smart young woman who had kind of insinuated her way into DLRC by painting the place first. There was painting going on. Anyway, she became friends with Judy [Heummann]. Judy was maybe the director of CIL, or codirector at that time.

Jacobson: Did you—

Lipton: Or deputy director. Julie was very interested in children's issues. So Julie and Arlene had started working on some 94-142 issues and were helping a couple of parents. We came there and told them what was going on in Richmond. That opened up, like, Richmond didn't know what hit them after that. Then, that was really the first time.

I've often talked about this at trainings, when we do trainings with parents. What it was like the first time I went to CIL because it was the first time in my life I'd ever seen people with disabilities, and pretty significant disabilities, like working, and on the phone, and just, kind of, doing a normal job kind of thing. I'd never seen anything like it. I was like, "Oh my God!" It was like, I'd never met any really disabled adults, at least none who had anything like Chloe's. It was another completely mind-blowing experience. Then to get to know a few of the people and realize they lived in their own apartments, they had crazy relationships like everyone else. They were just living and working like everybody else. I never could even picture that for Chloe before that.

Jacobson: Before that, did you ever think about Chloe's future or what would happen when she got older?

Lipton: I did think about it, but I couldn't picture anything. I had no—that's one of the things that was so painful and hard about having her and having her be disabled, because I could not picture a future for her other than my taking care of her until I died. That was what was so, for me, so scary and terrifying was I could not picture a future for her.

Rehab counseling at San Francisco State University

Jacobson: And where was Lenny in all this?

Lipton: Well, Lenny and I separated when Chloe was four. Chloe was definitely not the only reason we separated, because we had had problems on and off before she was born. But the stress of all of this certainly didn't help our marriage. It was very difficult for Lenny, the whole disability thing. I mean, he adored and loved Chloe and spent a lot of time with her. But it was harder for him. I've seen this with other families. It being harder for the fathers sometimes. I'm not exactly sure why. Emotionally, why it was harder.

But we separated when she was four. But he remained very involved, and lived near us, and saw her almost every day. By that time, I did go back to school. When she was about four years old, I went into a rehab counseling masters program at San Francisco State.

Jacobson: How did you pick that?

Lipton: Well, I was interested in counseling and psychology. Then I heard that if you go into this rehab program you could get money, a stipend, to go to school. It wasn't much money, but I thought, "Well, it's with people with disabilities. Well, I know something about that." I didn't really know what it was, to tell you the truth.

Jacobson: And that was before CIL.

Lipton: That was before that. If I had known, well, it was weird being in that program because there were maybe one or two people with disabilities out of maybe thirty, twenty-five or thirty students, but I felt like most of the people didn't have a clue about disability stuff.

I felt kind of out of it. I mean, isolated. I did have a couple of very good friends I made. But I felt the teachers didn't know, and plus the students didn't know. They had all the same kind of screwed up attitudes everybody else had.

I had one wonderful teacher there who taught counseling skills who also taught at Mount Zion and UCSF. She considered it her, she's very well known, Shirley Cooper. She'd written books about therapy and working with kids and adults. I once asked her why she taught in this rinky-dink program. She was just so much ahead of everybody else there. She said that she felt that Department of Rehab, and the Voc Rehab, which is where most of the people wound up getting jobs, was for some people with disabilities, the only time an opportunity to ever talk to anybody about their lives and what they wanted to do with their lives and family issues. She felt that it was important that the people that worked in those agencies know something. And she felt some kind of social obligation.

Because it was not a fancy job for her. It was just something she added on. But she felt some real obligation ethically that people who worked in those kinds of agencies be trained well and know what they were doing. I took as many classes with her as I could and admired her a lot and stayed in touch with her for a while.

Jacobson: Maybe we should stop here. I think somebody's at the door.

III. Involvement with Disability Law Resource Center, Parent Advocacy, Law School, 1979-1985

Connects with DLRC on Cameron School Issues, 1979

[Interview 3: June 12, 2001] [Tape 5, Side A]

Jacobson: Diane Lipton, session three, tape five. When we left off last time, you were talking about going to CIL and DLRC. First of all, what was DLRC?

Lipton: Well, DLRC was the Disability Law Resource Center. Mary Lou and Arlene and others could tell you more about its origin. And Judy Heumann. But basically it was the legal advocacy arm of CIL. It was headed by Bob Funk. Bob got grants from Legal Services, and other money, and basically started a legal advocacy unit. I think also the 504 training project was part of it, which was federally funded, and the KIDS [Keys to Integrating Disability in the Schools] Project, which was another project to do disability awareness in schools. But a lot of it was focused on employment and education. Rights of people with disabilities under state law and under mostly federal law. 504.

Jacobson: And what year was it when you became connected?

Lipton: I think it was, with DLRC, in 1979. Or maybe the end of '78. '78, '79. It was a little bit of time after DLRC had already started. And there were actually quite a few people working there. There were a number of different projects going on. Pretty quickly, it seemed, after it started. So anyway, that's when I—

Jacobson: So when you called up CIL, how did your call get directed to the right person?

Lipton: I know that seems like a miracle, given all the—[laughter] I guess we called CIL and told them we were parents, and we'd heard that they did some advocacy. We really weren't sure what services were provided. And then they referred us to DLRC. DLRC's office was across the street from CIL, where CIL is now. And it was kind of in this big, open area that became a pizza place. And anyway, we did actually get referred to the right place and people.

Jacobson: Was that when you met Mary Lou?

Lipton: I met, not immediately. I don't think I met her right away. At first we came and worked with Julie Landau, who was a parent advocate, at DLRC. And that's another story, how she got to do that work. She came and volunteered to help paint, when DLRC was first opening. And she really wanted to do parent advocacy. She was twenty-one or twenty-two, and just finished college. She had this complete focus about what it was she wanted to do. Anyway, right before we came, she and Arlene started to do some special ed [education] advocacy. I didn't meet, really get to know Mary Lou, until some time later.

Jacobson: Do you know where Arlene came from?

Lipton: Well, Arlene went to law school here at Boalt, and she just fell into the job.

Jacobson: At that time, was Judy around?

Lipton: Yes. Judy was the deputy director. I think it was largely because of Judy's interest in children's issues that Julie was able to convince Judy that they should do this parent advocacy. And Arlene was one of the lawyers. She worked with Phil Silver. And Shirley—I can't remember Shirley's last name—was another lawyer there. Bob Funk and Arlene. And Arlene was interested in children's issues, too. But I think it was largely Judy, really, was very interested in it. She was promoting that DLRC get involved.

Jacobson: Okay. So then what happened?

Lipton: Well, Pam and I, Pam Steneberg, we came there for a couple of reasons. One, the immediate issue was that we'd gotten letters in the mail that all our kids' therapy was going to be reduced because they were going to have one or two physical therapists. And we knew, we had gone to that training I'd talked about last time. We knew that they weren't supposed to make changes in the kids' programs and services without going through the IEP process. So we knew this letter that all the parents had gotten was illegal. We also had other issues by that time about, we'd filed complaints with the Department of Education, which we were supposed to be able to do under IDEA and that was very ineffective. They had a terrible complaint procedure. The state did. And there were a number of other local issues.

Jacobson: What kind of complaints?

Lipton: Well, the complaint had to do with the cut back in services. And then a little later, we filed complaints about the segregation of the kids. That they were so segregated in this particular school in Richmond. This school for orthopedically handicapped kids. And those were the main issues at the time. Related services like OT and PT were very big issues to some of us who had young children. Also the segregation issues. And then the state's failure to properly investigate these complaints and come out with findings and enforce them.

Jacobson: Do you know, is this under Public Law 94-142?

Lipton: Yes. And that was originally called the Education for all Handicapped Children Act. And then I think it was 1990, it was changed to the Individuals with Disabilities Education Act. IDEA. To make the language more politically correct. But the same law. And so, yes, all of what I'm talking about, these violations of the law, what we thought were violations, were under 94-142. Yes. Also section 504. Because section 504 assured kids with disabilities who were disabled under 504 the right to also free, appropriate public education. And there were some sections specifically dealing with integration of kids with disabilities with kids without disabilities and the right to what services they needed to have a right to an appropriate education. So it was kind of both laws, although 94-142 is much more detailed about the rights of the children and their families and so forth.

Jacobson: So what happened at DLRC?

Lipton: Well, what happened—by the way, what I'm telling you about is in that book *Stepping Stones.* Julie documented a lot; she wrote that article. There's an article in there on the Richmond story.

Jacobson: I got it.

Lipton: And she wrote that chapter for the "Foundation of Child Development" for that book, quite a long time ago, ten, twelve years ago. Maybe more. And she really went through all of the records we have. So I think what she, her story's going to be much more accurate than my memory now. But, anyway, I haven't read it in so many years. I don't remember.

But at any rate, what happened was, we went there and we met with Julie and Arlene, and they confirmed that the things we thought were violations going on were violations, and we filed complaints with the Department of Education. We helped other parents. We started to do this grassroots organizing. And kind of masterminded by Julie and Arlene. And we told all the other parents. I remember making zillions of phone calls to parents at the time. And other parents were concerned, too, about—they were all concerned about therapies and other problems like that. There was mixed feelings about the integration, and we weren't really pushing that issue at the time. Mainly because we weren't really focused on that, yet.

Jacobson: Were these parents in the school district?

Lipton: Yes, we were talking mainly to parents whose kids were at that school, and most, not all of those kids had physical disabilities. Many of them also had cognitive disabilities of one degree or another, but there were some who only had physical disabilities. It was a real mixture of kids. So we were calling those parents. Some of whom we knew, because our kids had gone to that baby program I had talked about earlier We knew them from there. One thing that was good about having kids in separate schools and separate classes when they were young is that the parents got to know each other. It's not as easy now that kids are scattered and in regular nursery schools and kindergartens. It's harder to organize the parents now.

But anyway, at that time, it was easy to know who the parents were. And we'd see each other. So we called them and asked them—they were all really angry, too—about

getting this letter from the school. That was a big mistake the district made, sending this letter to parents saying that all of the kids' therapies were going to get cut. What we wound up doing was writing complaints for each of the parents, and putting them together in a book and giving it to the Department of Education.

From that we found out that there was this whole statewide screw-up in the provision of OT and PT services. They were provided by a sub agency of the Department of Health called Crippled Children's Services at the time. They eventually changed the name to California Children's Services. It's CCS. And the people who worked for CCS were these real old-time, old-fashioned sorts of therapists who really didn't see the connection between therapy and school. Or weren't interested in the connection particularly between therapy and school. And they just wanted to keep their medical model clinic of therapy. And whereas P.L. 94-142 was much more progressive than that, and was trying to promote and required a more multi-disciplinary approach to serving kids with disabilities—having all the people who worked with the child come to these IEP meetings and work together, and so forth, CCS didn't see themselves that way. They saw themselves as very medical. They also had an orthopedist who was horrible.

And they had these sort of eligibility criteria. First of all they wouldn't give therapy just for what they called maintenance. Kids that they thought were too retarded to benefit, they would serve less, give fewer services to. They had all these little rules and policies which were very offensive to parents. They also weren't all that interested in parent input. And there was a lot of hostility that increased between parents and the CCS.

And they had a clinic at this school. the OH [orthopedically handicapped] school, that our kids went to. Some of the therapists were nice who worked there and were very pleasant people and enjoyed the kids. It was run by a woman, I won't mention her name, who—I don't know if she ran it at the time, but she did later—who nobody could get along with at all.

Anyway, we talked to parents who were already pissed off at the whole situation, to put it mildly. And we put together this very organized kind of complaint book. Then, as I said, we found out that these same things were going on all over the state. You know, between CCS, the schools, and parents. Under the law, schools are responsible for these services. They can contract with agencies like CCS. But everything CCS did had to then be in accordance with the law. And CCS didn't like that.

Jacobson: So, in other words with CCS, if they thought that there was no room for improvement, they wouldn't provide therapy.

Lipton: Right. They either wouldn't provide it at all, or they would provide it for, like, once a month or something. If they thought the child wasn't going to improve, for one reason or another. You know, we're talking about really young kids.

Jacobson: Yes.

Lipton: And that they could predict, first of all, was pretty presumptuous. And second of all, the fact that the kids, whether or not they were going to improve, really needed the therapy to maintain the function they did have. CCS wasn't interested in it. And they were the only game in town, because the school district wouldn't contract with anybody else, or hire their own people at that time. That later changed. They also had their own orthopedist who headed each clinic, so even if your own doctor, your own pediatrician, your own orthopedist, wrote prescriptions for therapy and thought your child needed it, they didn't care what your doctor thought. They had their doctor. And their doctor followed their rules. No one liked their doctor, I remember. You'd do everything you could to avoid having to bring your kid to see this clinic doctor.

So there were problems. Parents really felt that they made these predictions that were inappropriate. And they had eligibility standards which were inappropriate and illegal. And nobody could reign them in or stop them. The school district wasn't too fond of CCS, either, because they weren't easy to work with. This is still true, by the way, in many counties around the state. They kind of want to do their own thing, and don't want anyone telling them what to do. They have a very medical model approach, and so forth.

Challenges the medical model, questions segregation

Jacobson: Can you talk about that for a moment? About the medical model? What was the medical model?

Lipton: Well, by medical model, first of all, you had to show medical necessity for needing their services. And when you're dealing with things like physical and occupational therapy, what does that mean, medical necessity? It seems to mean if your kid has surgery and needed therapy for a while, that was a medical necessity, but it was a standard that didn't really go with the standard of P.L. 94-142, which was just a more functional kind of model, and which you got those services if you needed them to benefit from special education. And for some kids, learning how to hold a fork, how to wash themselves, how to take care of themselves, was their education, or a big chunk of their education. CCS just didn't see it that way. They just saw whether or not you were going to get a contraction or—[interruption]

Jacobson: Okay. So we were talking about the medical model.

Lipton: Also, this whole idea of improvement was part of that medical model. It was like, you got therapy if you were going to get—well, not cured—but if you were going to improve. There wasn't any conception, really, of independent living as we think of it today. There was nothing like that. And there was no idea that maybe the environment needed to change very much. Everything was based on how far you were going to get to being "normal."

Jacobson: I remember it was based on proving how far were you going to get to be independent?

Lipton: Yes, and not need help, right. Or assistance.

Jacobson: Not need help or attendant services. Having employment. That's how independence was defined.

Lipton: That's absolutely, yes. And that was the case then that you weren't going to be independent if you were going to need assistance, and you weren't going to be able to live independently.

Jacobson: Right. Right.

Lipton: And so yes, they had a very narrow view of independence and independent living. It was extremely narrow, and that was because, and that's actually, that was what struck us when we went to CIL and DLRC. Because no one had told us that even people who needed assistance and who would always need assistance, could have any kind of an independent, or regular life. So when we went to CIL and DLRC we saw people working there who did use assistance, and so that whole distinction started to get blurry and less relevant in the way we were thinking. But that was light years ahead of what the school people and CCS were thinking. There was no, I mean, that insight that we had, which doesn't sound like much right now, or that realization that we had, was way ahead of where the agencies were at in terms of working with our kids.

And there was no connection between the independent living movement, which was gathering a lot of steam in the seventies and was very vocal and visible, with people who are providing services to disabled children. It was like two totally different worlds. And for myself as a parent, I mean I came from the education world to the independent living scene, it was very difficult to bring that message back to the schools, because when you tried to do that, they thought you were—and they would say these things, too—that you were being unrealistic. That you're in denial. That you're angry—it's anger at having a disabled child. I mean, literally, they would say those kinds of things to your face.

And gradually we realized that other people had to start bringing that message, not just us. We started to ask, I think, Judy and other people with disabilities to actually start participating. Like to come to the meetings, some of the IEP meetings about our kids. And to come and talk to other parents because they didn't really listen to us. They just thought we had, for psychological reasons, were not wanting to face the realities. So it was very painful to be misunderstood like that. And it made me angry. That's what made me angry. Their refusal to kind of be open and consider what we were saying.

Then when we got to the integration issue, then they really thought we were off our rockers. And it was because of Judy and others at CIL that really pushed us to question, why are our kids so segregated in these special schools. And had no contact with the nondisabled kids. And again when we raised these questions, that's what really made us question, yes, "Why are they so segregated?"

And for years we had felt so grateful that there was this school there, that there was anything there for them that looked like a school that wasn't in some dump in a basement, and that had materials and enthusiastic teachers and things like that. But eventually we started to really question this segregation. And again, they felt we were, even though the law has this very strong philosophy and requirements about kids being integrated. Disabled kids and being educated in regular classes and regular settings with nondisabled kids to the maximum extent appropriate. It's very progressive in that way. It didn't matter. The schools didn't know what that meant, and they just chose to

ignore it. So we started pushing that issue. And then they really thought we were losing it.

And we started small. Like I asked why Chloe couldn't go to the regular kindergarten class. Mind you, this was two schools on the same block. I mean, it wasn't like there was even a transportation issue or anything. Why she couldn't go to the regular kindergarten class a couple of afternoons a week for story time or music time?

Jacobson: What did they tell you?

Lipton: They said, well, it would be nice, but it's logistically difficult. They had a lot of excuses why they couldn't do that. I don't know if the principal of the regular school was too in favor of it. And what I wound up having to do, is Wayne Sailor, who is very, very well known in education circles as being one of the leaders in the whole movement to have kids integrated, disabled kids. He was becoming nationally known.

[Tape 5, Side B]

Jacobson: Tape five, side B. So who was Wayne Sailor?

Lipton: Wayne was a professor at San Francisco State University in the special ed department where they trained special ed teachers. He was one of the university people in the country who was really focused on this integration issue. He ran an institute there that had a lot of federal grants and they were doing research on the benefits of integration to both disabled and nondisabled kids. And they were also starting to train teachers in how to integrate kids. There was another person, Lou Brown, who's a professor at the University of Wisconsin, Madison. There were a few people around the country at the universities really pushing this strongly. Still they weren't connected to the independent living movement. Now they're very closely connected. It's interesting how that happened.

Jacobson: How did they find you or how did you find them?

Lipton: You know, I'm not sure. I think Julie Landau, for some reason, knew of Wayne. And knew some of the people at the special ed department at San Francisco State. So somehow or another I got to meet Wayne and know Wayne. And he was getting very well known at the time. And I asked him if he would come to Chloe's IEP meeting. So he did. And it kind of blew the school district away that I had this professor come and talk about, there's no question that but she should be integrated. And they're starting to do it here and there in this place and that place. And no problem, you've got the perfect place to do it. The regular school's right here. And he just came in like there's just no question that this should happen.

Unlike the therapy issue, there were parents who were queasy about it, I would say. They thought their kids would get teased, that they wouldn't be treated well. They just didn't really see the benefits for their kids for one reason or another. It felt safer to have them in the special school. They couldn't really picture how their kids would function in regular classes. Even the kids who only had physical disabilities. So there was a lot more ambivalence from the parents on that issue, and these other bureaucrat types really couldn't, they really had no answer. There's no reason that they shouldn't do it other than it's inconvenient or the principal might not like it, or a teacher might not like it. But there was no educational or philosophical reason. Or legal reason that they could object to it. So he brought this authority that I did not bring. So they agreed to do some integration, but it never really happened right. I mean, getting them to do it right, and on a regular basis, was very difficult, and there were few other parents who wanted it.

But we started to file complaints about that, too, with the state Department of Education, because we knew the law required this mainstreaming or integration to the maximum extent appropriate. Kids were supposed to be in regular classes with supplementary aids and services and only be removed from that setting for part of the time or all of the time if there was some compelling educational reason. And there were no such reasons. And some of the kids, most of the kids, had no integration whatsoever. This became our next big issue. In the meantime, we had kind of organized the whole state on OT and PT issues, because there were some advocates in other parts of the state who were realizing, coming to the same conclusions we were.

Bureau of Education for the Handicapped withholds federal funds, 1980

Jacobson: Now when you say we, was DLRC helping you and Pam?

Lipton: Yes. The DLRC was helping us. They would come to our IEP meetings. They helped us strategize. And Pam and I were like the foot soldiers. Yes, I mean they basically were doing strategizing with us about what to do, and Pam and I did sort of a lot of, initially the leg work of calling all the parents and having parent meetings. But we were encouraged and supported by DLRC. Completely.

Jacobson: And this was around 197-?

Lipton: Around '79 and '80.

Jacobson: How old was Chloe at that time?

Lipton: Well she was born in '72, so she was seven or eight at that time. And one of the things we wound up doing, and I think this was in the '79-'80 school year, we not really knowing, having much experience, we had contacted the Bureau of Education for the Handicapped [BEH].

Because Judy Heumann knew some of the people there. And they were the people who, in the department, well actually it was part of HEW [Health, Education, and Welfare], I think, then.

Jacobson: Yes.

Lipton: They were the people at BEH, who were responsible for overseeing the special ed program and monitoring that the states which got the federal money were doing what they were supposed to be doing and complying with the law. So through Judy, we got to talk to a couple of the people there who ran it. We told them what was going on in California and they were interested in what was happening here. We wound up going to Washington, Julie and I and, I can't remember if Pam came with us or not. We went a

couple of times. We didn't know how to dress. I don't know; it was just these hilarious trips.

We would just kind of barge into these offices. We didn't really know who these people were at BEH—if they had big jobs, or what. We just kind of knocked on their doors, and they were really interested. Martin Gary was there. Ed Martin. People who were real kind of leaders in the early days of special ed. So we had these meetings with them. We had everything incredibly well documented, thanks to DLRC. We had complaint letters from parents all over the state demonstrating their policies, particularly around therapy. We had letters and documentation to show how badly California was handling complaints. And they're supposed to have a complaint system that has certain minimum requirements. And it was very bad here. All of these things were problems all over the country. We just, we were very organized in knowing what was happening here. And also in our presentation of the issues.

So they were interested in doing something. It was like an opportunity for the Washington people to act. I don't know why, we were running from office to office and we didn't have appointments with most of the people we saw. It was just kind of a very grassroots kind of trip to Washington.

What resulted from that was they decided that they were not going to give California their federal funds which, at that time, was 80 million dollars a year—now it's, I don't know, 350 million or something a year—until California came into compliance with these issues. They didn't go through the formal process of holding up federal funds, but they were calling it a delay. They actually delayed funds. And there's all this correspondence back and forth between BEH in Washington and the California Department of Ed about what Department of Ed needed to do here in California. It kind of amazed us that a few people with support from parents all over the state were able to pull this off, and it infuriated the Department of Education. It really infuriated our school district, Richmond, because Richmond was kind of the center of it. I think nobody could believe it was happening. And one of the reasons Richmond was so upset was some of the key special ed people were funded by federal funds. Naturally they started to get worried about losing their jobs if the funds didn't flow.

Jacobson: So BEH was providing the funds for the whole Department of Education, not just for special ed?

Lipton: No, these were special ed funds, and the special ed funds that the state gets from the federal government, which was a fraction of the cost of paying for special ed, but a significant amount of money. And it was like no one knew how—how did this happen? Everyone was sort of surprised. And for parents who were involved, which, by that time, there were more parents who were involved than Pam and I. There were some parents in southern California, and more parents in northern California. It was incredibly empowering. It was like our first attempt to do something was so successful, we couldn't believe it. At that point, we had no problem having meetings with anyone in the state. I mean, they would talk to us and meet with us. It created a lot of problems for Pam and I locally in our school district, because suddenly Richmond was on the map. Everyone in Washington in the special ed in BEH had heard of Richmond now. Richmond, California. But they were very angry. And very hostile to us.

— 40 —

Repercussions from empowerment

Jacobson: What were the repercussions?

Lipton: Well, the repercussions for our kids were not negative, because our kids got more than other kids, I would say. Certainly more integration, whatever. I mean, it was still pretty minimal at the time. The services that our kids got maybe were a little more than what other kids were getting. If anything, it was beneficial to our children. And to all the kids, really. Especially in Richmond. Because they started to realize they had to be careful. Also, one thing that we had in our favor, going for us, that made it easier, was that we had good relationships with our kids' teachers. They agreed with us on—the teachers at the school had mixed feelings about integration. A couple of them thought we were really right, what we were doing. And then there were some who didn't really agree. Our kids' teachers might, you know, Chloe's teachers were not, I wouldn't say they were totally gung-ho on it, but they also thought it was probably right what we were doing. And so we weren't, I was never worried about Chloe being ill treated because of the advocacy we were doing. I worked hard to maintain really good relationships with the teachers. And we also just lucked out. They were very conscientious, good people who would never, even if they strongly disagreed with me, would never have taken it out on Chloe.

Jacobson: But you said that it became harder for parents. How?

Lipton: Well, there were no negative repercussions for Chloe. There were for me, personally. Because we'd go to the IEP meetings, and they would always erupt in some big argument. It is really difficult to always sort of be in that position. It was not a feeling—even if there was agreement between the teacher and myself, the administrators were so angry. I was such a big pain to them, so pushy and demanding. That it became very negative, those meetings. And our relationship with the administration became very, extremely strained. At one point, this was maybe a couple of years later, in every school district they're supposed to have an advisory committee of parents, teachers, administrators, to kind of guide policy in the district and implementation of the law, though it had no real authority.

But under the law, every district is supposed to have one of these, and the way you got on it was, somebody had to nominate you. Then the Board of Education had to approve you. And I kept getting nominated, but I never was approved to be on that committee or any other committee in Richmond. I had a meeting with one of the administrators, not about that, but that issue came up. And he told me that as long as he worked in Richmond, I would never be on any committee. Period. So that's, I was surprised he would even say such a thing to me.

So there was this hostility. Going to Chloe's IEP meetings was always just full of dread. I knew I'd be asking for things they wouldn't like, they wouldn't agree with. Chloe's father, who, he and I were divorced at this point, but he would come to the meetings, and I'd beg him to not lose it in the meetings. It was just very, very difficult to advocate for her needs. They were just so ready to be angry and think I was crazy. Then when I look back at it, I think that our demands were really modest.

— 41 —

Jacobson: Could you give me an example?

Lipton: Well, like integration. It took a long time. We were just asking for like two or three times a week, if she could go to story time or music time in the regular kindergarten. Or, as she got older, the regular first grade and second grade. That kind of thing. And that's pretty modest, certainly by today's standards. Even then. And that was a big fight. Then we got to a point—

Jacobson: What would they say?

Lipton: They would say yes, we could do it, but we have to see what their schedule is, and our schedule. And do we have enough staff to have somebody take Chloe up there? And I'd say, "Well, Chloe doesn't have to go alone. Other kids from her class could go. And, in fact it would be better if she didn't go alone because it would be less awkward for her to not be the only one." Everything I would suggest to try to counter their problems, there's always some reason. So she never did actually, on any regular basis, do any of those things.

Then we started to step up the advocacy. And we started to question why, okay, they have all these reasons why it was not convenient or easy or blah blah blah. So the next question is well why do these kids have to be in these separate schools? Why can't they at least be in separate classes in regular schools? And then that would make it easier to do all this stuff. So we started to really question the existence of the separate schools.

And then, that was really like revolution. Well, in Julie's article, she really documents that particular issue and how the kind of advocacy we did, which was, again, we'd file zillions of complaints. And we talked to the feds about that issue. And there was a lot of pressure on the school district at that point. Eventually, I think in the early eighties, they decided to close all the special schools and to move the classes into regular public schools. I think it coincided with there were some real practical reason that the school district had for making that decision. For one thing, I think they thought it would be cheaper than having to maintain these separate schools. At the time, enrollment was down and there was space in the regular schools. More space to do this.

Anyway, there were some, and the county ran two of the schools, and the county and the district didn't get along. So there were a bunch of practical reasons why it suited the district. Also I think they could, to some degree, see the handwriting on the wall that there were going to be more and more challenges to the kids being in separate schools, because it was very difficult to do any kind of meaningful integration when they're in separate schools.

Parent advocate at DLRC, 1979-83

Jacobson: At this time, were you working?

Lipton: Yes. I was a single parent with Chloe, although her father helped a lot to take care of her. I was working for the Department of Rehabilitation, half time, as a rehab counselor, and half time, DLRC hired me to work as a parent advocate. And they hired two other parents.

Jacobson: Who?

Lipton: Lynn Gray, who now uses her maiden name, Lynn Jehle, who's still in Berkeley, and Bev Bertania. And the three of us worked part time, or half time each, at DLRC, starting to help other parents. By this time, we knew the law, really well. The three of us did. And then DLRC was getting calls from parents all over the place to help with advocacy. So we would work with those parents. And we started doing training for parents.

Then, meantime, DLRC was doing these big 504 trainings around the country, and then they did a couple on education. And that was the beginning of, I guess that was also around '80. Before DLRC became DREDF [Disability Rights Education and Defense Fund]. Right before. We started to have more contact with people at DLRC doing other things. Like Mary Lou. And I felt like the people at DLRC, at that time, it seemed like there were an awful lot of people working there, like thirty or forty. I don't know if they were all full time, but it was like a happening place. They were getting a lot of federal money to do trainings and all kinds of other projects. But we kind of had our own little separate world there. I think it was because P.L. 94-142 was going to be a training, or part of a training in a separate, and/or, also a separate training that 504 people were going to put together. And they did everything in a very professional, first-rate, quality way. I mean, the materials were excellent. The presenters, there was lots of training on how to train. I don't know if you ever met Al Kalminoff, if you knew him?

Jacobson: No.

Lipton: You know who he is?

Jacobson: I've heard his name mentioned.

Lipton: He was working with people on how to train and how to make presentations. It was a very high-quality training program. And Mary Lou, I don't know if she ran it or was one of the people who ran it, but at that time, when the issues started to merge, or the trainings would kind of merge a little bit, that's when I started, I think, to talk to Mary Lou for the first time. I mean more than kind of in passing. And some of the other disabled people who worked there.

Jacobson: Who else were—

Lipton: Well, Bob Funk, who was the head of it, he was very open to the kid stuff from the beginning, or at least it seemed to me he was. And very friendly to us in what we were doing. And very supportive. Extremely supportive. There was A.J. Do you know A.J.?

Jacobson: A.J. [Smalldone?].

Lipton: Yes. A.J.'s desk was right next to Julie's, so we used to talk to A.J. Actually, for a long time we didn't have desks, so we would work on the floor between A.J.'s desk and Julie's desk. We would talk to her, and of course she was very friendly and interested in what we were doing. Let's see, who else—there were other people, too. I'm just sort of not thinking right now. And then there were a bunch of people there who I hardly ever talked to. We just didn't cross paths, basically. But I did start to talk to Mary Lou and the people who were doing the trainings, and one day we got into kind of an argument.

Jacobson: With Mary Lou?

Lipton: With Mary Lou. About the role of parents. I really almost can't remember what it was about anymore. I think the essence of it was that there was some questioning of whether parents really knew what was best for the kids, and that people with disabilities did know, adults with disabilities. And the parents were just kind of a force for keeping the kids back, holding the kids back. There is some truth to that. And I think that was more so at that time.

But from my perspective it seemed like, I saw another side of it. I saw parents struggling every day to advocate. To get important things for their kids. And parents who were very in touch with their kids' needs. I think there was a real need for parents to see what's possible for people with disabilities. And the degree of independence that their kids could have as adults, whether or not they need assistance. So I thought it was very important for people with disabilities to get involved in special ed, because I thought parents did have a lot to learn from them and to see. But Mary Lou, and many, I think this was not uncommon at the time, really saw parents as kind of, you're getting in the way.

Jacobson: Mary Lou said that she met you—

Common bonds between independent living and parent advocacy movement

[Tape 6, Side A]

Jacobson: Interview three, tape six, with Diane Lipton. So you were about to tell me about your discussion with Mary Lou.

Lipton: My discussion with her. I don't know how much you had got of what I was saying, but it was really, her point of view, as I remember it, and I may be misstating it in retrospect, was that parents of kids with disabilities were holding them back, and I felt that wasn't true. I mean, it was true to the extent that parents had not been exposed to what's possible for their kids, and in that respect, I felt that disabled adults had a really important role to play. But I didn't think that parents in general were sort of useless and as in the way as I thought Mary Lou was saying.

Jacobson: You said that at the time you were calling on parents and some of them agreed with you about the therapy, but not the integration. What were your thoughts about their feelings about integration?

Lipton: Well, I had a couple of thoughts. One is that a lot of the parents really did not have the same, come from the same background I did, where it was kind of easy to question authority. I mean, not that it was so easy, always. But I was brought up to not see people in authority as having all the answers. And then my involvement in political and social causes certainly reinforced that. So it wasn't as big of a deal for me. [someone enters room, greets them]

Jacobson: That was my son David.

Lipton: He's very handsome. Adorable.

Jacobson: Thank you. I have nothing to do with it. [laughs]

Lipton: He's very cute, whoever's responsible.

Jacobson: I have to agree.

Lipton: Let's see. So that was one issue, I think, and I came from the university in Berkeley and all the political and everything. So questioning authority was not unfamiliar or as intimidating to me as it was to a lot of the parents who didn't have those experiences. So that was one issue, and they knew questioning the integration stuff was getting into a more controversial area than questioning why their kids weren't getting enough therapy.

So that was part of it. The other part is, I think, parents just didn't know, they couldn't kind of envision how their kids could fit in, and as I said earlier, parents were worried about teasing and safety and whether their kids would get enough attention. All of those, I felt, were legitimate concerns. But what I had been exposed to with, first of all, just through CIL and DLRC, was seeing disabled adults doing things and living a certain way, or living a variety of ways, that a lot of parents hadn't seen and really didn't know was possible for their kids. And then I had gotten to know the university people who really felt strongly that kids would, first of all, get a better education and, secondly, would be able to develop the social skills that they were going to need if they were going to live independently and not in institutions. Those people, a lot of them came out of the de-institutionalization movement, actually. The university people sort of had some of their roots in that.

So I just saw the other parents as being scared to really stand up for it, and also just not knowing. So one of the things that we did was organize some trainings for parents on it. We had two teachers—their both names were Blair. Blair and Blair—who were special ed teachers. And one of them, I still worked with a lot over the years. She left teaching and started to do more consulting and research.

Jacobson: What was her last name?

Lipton: Her last name is Rogers. She actually became well known in this field of special ed and integration and inclusion. But they were both teaching in Alameda at the time. They were special ed teachers; they had special ed separate classes in regular schools. And they were really pushing for a lot of integration of their kids. They came and spoke to the parents about how they did it, what the benefits were, why they thought it was really important, how it's not such a big deal, and it was great for the nondisabled kids. And we had a couple of the university people come. We realized that parents needed more training information before, so that they could really understand the issue more. I don't know if Judy came, but a couple of disabled adults came and talked about it also with the parents.

Jacobson: What grade did Cameron school go up to?

Lipton: It went from kindergarten to high school. And the last couple of years before they closed it, some of the high school age kids were going to the regular high school for a couple of classes. But, do you know Carla Toff?

Jacobson: No.

Lipton: She went to Cameron through her whole—I think she went to UC Berkeley eventually. But she was like one of the stars of the school.

Jacobson: When you say high school age, was it a law that said that disabled kids had to be in education until they either graduated or were twenty-one?

Lipton: Yes. Right. The law says that there are obligations of the school district to provide an education for disabled kids until either graduation from high school or can go up to age twenty-two. Right.

Jacobson: So there were kids in that school who could have been twenty or twenty-one, right?

Lipton: There could have been. I don't remember that there were. There probably were a couple. Those kids, no, I think I know, actually. The older kids there, who had been going there for many years, mainly were kids with physical disabilities. Not only, but, I mean, mainly had physical disabilities. So the kids who tended to stay till age twenty-two usually have cognitive disabilities, and those kids were kind of tracked off into a different school. They stayed either at the development center, where Chloe was initially, or, if they didn't have substantial physical disabilities, went to one of the two, there are two MR [Mental Retardation] schools. Schools for mentally retarded kids. In the district.

So there were four schools. The older kids at Cameron tended to be just kids with physical disabilities, and seemed to leave there when they were eighteen or nineteen, as far as I can—and they started to integrate those kids more at the end. They were going to the regular high school for some things. The population of the younger kids, or the kids in the middle ages, had more multiple disabilities. Cameron School was originally really just for physically disabled kids. And then they started to take kids with other stuff. But if they were too mentally retarded, they got sent to one of these other places. It was a very stratified sort of—

Jacobson: I didn't mean to—

Lipton: To go off. Yes. I was just trying to remember—

— 46 —

Jacobson: So we were talking about parents and you were saying that you had workshops with them. And were they about educating them to the laws, or about possibilities of independent living? Or both?

Lipton: It was kind of both. The focus was more on school issues, but the context of the whole thing was that if school is to prepare you for something, we have to start thinking about what is there out there. And that is where the disabled adults could come in and talk about independent living and what's possible. So it was kind of in that context. And then if the kids were going to be ready to live independently, however that might be, they really had to start getting the education and the skills. They needed to do that.

Jacobson: Going back to Mary Lou, did she ever come around?

Lipton: Oh, she came around big time. Yes, she did. And very much so. I think she, what I later understood, not even that much later, was for Mary Lou and a lot of disabled adults of her generation, there were a lot of issues about parents being either overprotective, or also not knowing what was possible for them. Those were real issues. And that a lot of her generation felt a lot of anger and resentment toward their parents, that their parents didn't push them or help them enough in that direction.

So I guess I came to see emotionally and psychologically, that for a lot of disabled adults, they did have a lot of struggles with their parents. And Mary Lou came to see that a lot of that was because of a lack of exposure the parents had had. But she also came to really, really respect parents, the parents who were out there aggressively advocating for their kids and making changes. And what we gradually came to see was that the interests of the parent movement, which at that time, the parent movement and the independent living movement were separate. They were like on two parallel tracks, with very little contact between the two, generally. And what Mary Lou and I came to see, and I'm sure many others did, too, was that we really had the same interests. And that if we worked together, there would be a lot more strength in numbers and strength in perspectives and experience. Mary Lou turned around just enormously because she got it way before a lot of other disabled adults did. She was very moved, I think, by the passion with which parents came to the issues and were willing to kind of get out there and fight—usually fighting for the same things that the independent living movement has fought for.

Parent advocate role on Area Board V

Jacobson: Where did Area Board V come in?

Lipton: The federal Developmental Disabilities Act, I think set up some kind of a developmental disability system throughout the country of advocating for people with developmental disabilities. So there was some federal money for that, and some state money. And the area boards, I think there are ten or eleven in California, do sort of systemic advocacy. They don't really have any real authority to do much. They can bring lawsuits, which they have once or twice. But they are kind of a force for

advocacy in the community for people with developmental disabilities. Are you asking about it because I worked for them?

Jacobson: Yes. How did you get on it and what was the relationship to what you were doing?

Lipton: Well, I think what happened was, in 1980—was that when Reagan came?

Jacobson: Yes—

Lipton: As president. And the first thing, he was into this whole deregulation thing.

Jacobson: Right.

Lipton: Well, the first regulations he chose to try to attempt to deregulate were the regulations for 94-142 and 504. And he picked the wrong group. The Department of Education, I guess it was still BEH then, but under Reagan's administration, came out with these horrible proposed regulations to weaken all of the rights, greatly weaken the rights of disabled kids and parents under the federal law. He was going to do the same, or started to do the same, with 504 regs. At that time, I think it might have been when DLRC was ending and DREDF was just beginning. There wasn't any money to do any special education stuff at DREDF, for a period of time. And so the area board hired me to do special ed work.

What I did there was work with DREDF on writing comments to the new proposed regulations and organizing parents against the regulations. That's also when I got to know Mary Lou better, because BEH was holding hearings. Or maybe it [BEH] had already broken into HHS and the

Department of Ed.

Jacobson: HHS?

Lipton: HHS.

Jacobson: Which is?

Lipton: Health and Human Services. When did that happen that HEW separated? It was around then, I think.

Jacobson: I can't remember.

Lipton: So it was either the US Department of Ed, or still BEH, I'm not sure. But anyway, as part of the regulatory process, they were holding hearings on these proposed changes to the special ed regs around the country. And I remember Mary Lou, DREDF, helping a lot with organizing the parents to appear at the hearings to help write testimony at the hearings. They were in L.A. And I was able to continue that work at the area board.

Jacobson: What happened to the money that DLRC got from parents' education? Did it dry up?

Lipton: I don't know that they ever got federal money for that. Or if they were using Legal Service's money. I'm really not sure. But at any rate, when it was changing to DREDF, there was no money specifically earmarked for that work. For some period of time.

— 48 —

Jacobson: Were you around when DLRC became DREDF? How did that happen?

Lipton: You know, I'm not the best person to talk to about it. And you know there's a lot of politics around it.

Jacobson: Okay. Yes.

Lipton: The reason I say I'm not is, first of all, I really wasn't involved in any of the discussions about it. I just heard everything second and third hand. Arlene and Mary Lou and those could really talk about it.

Jacobson: It's probably covered in Mary Lou's and Arlene's interviews—

Lipton: Yes, I would think it would be. Because she was very involved with that.

Begins law school

Jacobson: So you were more on the periphery. Had you gone back to school at that time?

Lipton: Yes. One of the reasons I was not more involved with DREDF, at the time, was I started going to law school. In 1980.

Jacobson: Where?

Lipton: At Golden Gate University. Because they had a night program. A part-time program. The reason I went there was because Julie Landau had decided to go to law school. And we had become very good close personal friends.

Jacobson: So she was not a lawyer?

Lipton: She was not a lawyer, but she knew the law and, I mean, really well. And she knew a lot of the cases. She was a great strategist and all those things. But she decided to go to law school, to Golden Gate because also she needed to work during the day. She was going to go at night. And she applied, and got in, of course.

Then she said to me one day, this was like maybe in April, and she was going to start school in September. Or May, even, it might have been. She said, "Why don't you come to law school, too?" Like, "Why don't you come to the movies with us?" [laughs] And I thought hmm. I don't know. Well, okay. Literally, it was like that. I said, "But it's too late to apply now." And I was getting more and more interested; I was very interested in the legal aspects of what we were doing. I liked looking at the laws and reading them and understanding that stuff.

So anyway, Bob Funk or Paul Silver—one of them knew someone at Golden Gate—called them and said that I wanted to apply. And it was way past the time and everything, but they said to send in the application. And I did. I took the LSAT in the beginning of June. I guess Bob, Paul, and Arlene wrote really great letters of recommendation. But one of them knew someone at Golden Gate, and they accepted me, much to my amazement, because it was so late. So before I knew it, I was going to law school with Julie, and working, and taking care of Chloe. I really don't know how I did it, because just the thought of it now is exhausting. I guess I was pretty interested and motivated.

Jacobson: Did you have your family's or exhusband's support with Chloe?

Lipton: Well, I had a lot of support. My father was a lawyer, but I never was interested in law. But I guess I was around it. Or, I don't know, we never talked about it that much at home. I wasn't that interested. But anyway, I guess I absorbed something about it from home. And it didn't seem so foreign, the idea of being a lawyer. Anyway, when I told my parents I was going to go to law school, they were really, really supportive. They thought it was great. They helped me financially because it was really expensive and I was just working half time. For a while I had two half-time jobs, but then I couldn't keep that up, and so they helped me financially so I could have enough help with Chloe. Then Chloe's father was taking care of her a lot. And then I met Jim in the middle of law school.

Jacobson: You were working part time with the area board?

Lipton: I think it was part time.

Jacobson: So you had left DR [Department of Rehabilitation]?

Lipton: I left DR and I left DLRC. And then I worked at the area board. Not that long, maybe a year or two or something.

Jacobson: Where did you meet Jim?

Lipton: Actually, I didn't leave DR for a while. I think I kept that job while I was in law school. For a couple of years, anyway. I met Jim when, actually, the first time I met him was when I was in the masters program for rehab counseling, when Chloe was about three or four. I did an internship at Mount Zion Hospital with adolescent kids in a day treatment center, and Jim was their rehab counselor from DR.

Jacobson: What's his last name?

Lipton: Armstrong. And he was working in the San Francisco district then. So I met him then. As I said, some of the kids I was working with were clients of his so he would come to Mount Zion and meet with them—

Remarriage, birth of second daughter, work at Disability Rights Education and Defense Fund

[Interview 4: June 29, 2001] [Tape 7, Side A]

Jacobson: Diane, tell me about working at DREDF.

Lipton: Well, DREDF was started in, I guess, 1979. 1980. And for five years—I think we left off where I started to go to law school.

Jacobson: Yes.

Lipton: So from '80 to '85, I was in law school. I went part time. And then had a second child in the middle of it. When Daria was born.

Jacobson: And you met Jim in between.

Lipton: Right. I had met Jim a while before, but barely knew him. And I met Jim, I guess it was in '80, or '81.

Jacobson: Where did you reconnect?

Lipton: We reconnected at a union convention. The rehabilitation counselors. I guess I must have still been working part time for rehab then. Rehab counselors are part of the AFSCME local. And the union then was very—

Jacobson: What local?

Lipton: It might have been 2620.

Jacobson: AFSCME?

Lipton: AFSCME. I don't know why that number comes to my mind, but—

Jacobson: But what does AFSCME stand for?

Lipton: Oh, it's American Federation of State, County and Municipal Employees.

Jacobson: OK.

Lipton: It's one of the big public job—what do you call it? I'm blanking. Anyway, public sector unions. Unions that represent public employees.

Jacobson: And Jim was a rehab counselor?

Lipton: He was a rehab counselor at the time and so was I, but we were in different offices. He worked in San Francisco and I worked in Pleasant Hill. So at the conventions, which in those years were very well attended, and there was a lot of enthusiasm, that local had just been organized. So we reconnected there. He told me he was going to be moving from San Francisco to Berkeley. I told him to call me when he moved to Berkeley because I lived near there, and we'd get together. Anyway, he did. We got together. And we've been together ever since.

I guess that must have been in 1980, or almost '81, because I was in law school. And then in the middle of law school, in '83, our daughter Daria was born. I took a semester off, and a summer off. I wound up graduating from law school in 1985. During that time, I held some contact with DREDF. Well, I was friends with people who worked there. But I would work on, occasionally, a project there, and I did some sort of an internship—a loose one. When I finished law school, I passed the bar, I started looking for jobs kind of briefly. And I was working, for DREDF. At that time, DREDF had lost all of its federal funds. It was during Reagan years.

IV. Disability Rights Education and Defense Fund, 1985-Present

Funding for DREDF: the early history

Jacobson: At that time, was DREDF already separate from the CIL?

Lipton: Yes. It became separate from CIL, I think, in 1979.

Jacobson: Okay.

Lipton: Yes. Yes. I think it was '79. It became a completely separate legal organization., although many of the same people worked in it when it was connected to CIL. It was the same people.

Jacobson: Do you know why it separated?

Lipton: Well, one reason, I think, was because the idea of DREDF was really to create a disability legal defense fund modeled after other legal defense funds, like the NAACP Legal Defense Fund, the Women's Legal Defense Fund. So there was kind of a concept or a vision of creating that kind of civil rights defense fund that would do large impact cases. Work on policy. So I think partly it was because it was envisioned as being this kind of organization. It probably, maybe didn't fit into being part of CIL. There may have been other reasons, too—political, personal, financial—I really kind of wasn't privy to all that went on at that time.

Jacobson: So you were a parent consultant?

Lipton: Yes, during those early years. And every once in a while, DREDF would have some grant and they would ask me if I could help on it a little bit, which I did. Not hugely, because I was in law school and had a baby and Chloe. But I definitely kept connected. And then, when I finished school, I started working here immediately, helping to write grant proposals, because DREDF lost all, most, not all, but almost all of its federal funding, which happened to a lot of public interest organizations in the early eighties. It had to start looking to private foundations and other fund-raising mechanisms.

Jacobson: Now when they did get federal funding, where did the funds come from? What department?

Lipton: I think they must have come from what was then HEW. That was the money that supported all the national 504 trainings that DREDF was doing, and a number of other projects. But that money really dried up. DREDF went from a staff of forty or fifty people to like six people. It really changed dramatically. The people who stayed involved, the leaders of the organization, had to start looking at a whole different way to fund the organization. I was kind of looking for a job and had time, so I worked at DREDF just writing grant proposals and trying to help with other fund-raising activities.

Jacobson: Where were you looking for money?

Lipton: I can't remember specifically now but various private foundations. Corporations like Clorox. I remember Clorox. I don't remember which ones. I was trying to develop a donor base, an individual donor base. But I did that for just a few months, because after I was doing that for a few months, one of the other lawyers who worked at DREDF, left. And she had been doing a lot of special ed. Actually, I did a little bit of stuff with her while I was doing this fund-raising.

Jacobson: Who was that?

Lipton: It was Kim Swain. Kim went to work for protection and advocacy, so I just moved into her job. It was great for me. There weren't any interviews or anything, because I had worked with everyone—you know, Mary Lou and Arlene—on and off for a long time. So anyway, it worked out great for me because it was exactly what I wanted to do. So since 1985, I've been at DREDF as an attorney. Right now mostly I do, and have done, over the years, education litigation, and state and federal policy work. I've represented parents in a zillion IEP meetings. And everything from going to a little local IEP meetings for one kid to doing stuff in DC on broader national policy.

Children with Disabilities and Family Support Project; Parent Training and Information Center

Jacobson: I asked, or did I ask, what you were doing at DREDF. I have in my notes the CDFS project.

Lipton: CDFS? Children's defense fund?

Jacobson: It was the Children with Disabilities and Family Support Project.

Lipton: Well, I guess what happened in the middle or late eighties is we started to get federal money again to support parent work. We were doing a number of things under this Children with Disabilities Family Support Project, mainly providing technical assistance to parents who called on the phone about special education issues, or other education issues. We became what's called a Parent Training and Information Center.

That is a project that's federally funded, and it kind of came under this Children's Support Project. It was a project of the project. But basically the project was all one. It was just the federal funds helped finance part of it.

Jacobson: Were the federal funds available because of IDEA or 504?

Lipton: Was that why we got federal funds?

Jacobson: Yes.

Lipton: Yes. The federal government, which I think by then was the Department of Education, decided that—well, I think it's in the law itself—that there should be a network of parent training centers around the country to advise parents about their rights and provide training. Give them information about their children's disabilities, and so forth. And that's in the federal law.

Jacobson: And was this after [Ronald]Reagan, during [George Herbert Walker] Bush?

Lipton: It must have been. Bush was president from '88 to '92?

Jacobson: Yes.

Lipton: So it must have started toward the end of the Reagan administration. Yes, I think it did, but I'm not absolutely certain. And maybe it was added to the law as an amendment setting up these parent training and information [PTI] centers. I really don't remember the history of that very well. But there was supposed to be what's called a PTI center in every state. And actually there are a lot more than that now. There must be, I don't know, eighty or ninety? Something like that—a network of these parent training and information centers. We used to get a lot of calls from some of the other parent training and information centers about legal issues that they had questions about, because our parent center was part of a bigger disability, civil rights law center. Most of the PTIs around the country are just their own separate organizations. They're not part of another organization. They only do parent and family work. They're not legal organizations. So we were a little bit unique in that way.

DREDF's civil rights strategy; precursor to drafting of Americans with Disabilities Act

Jacobson: What was the rest of DREDF doing? Were they doing 504? Were they working on the ADA [Americans with Disabilities Act]?

Lipton: Yes, they were doing 504. Then in the very late eighties, we started working on the ADA. Mostly Arlene and Mary Lou and others, a couple of others, at DREDF. Pat [Patrisha Wright], of course, in Washington. And that consumed a lot of DREDF's resources and time.

Jacobson: Were they writing the ADA or lobbying?

Lipton: They were actually drafting. Working with congressional staff. I don't know how much of this is supposed to be public. But anyway, they were actually drafting language with congressional staff. There were endless meetings about different aspects of it with disability organizations and with members of Congress and their staff. The process took a few years, until 1990, when it was passed. So two or three years of very intensive work.

Then there was the lobbying piece of it. Pat was working in Washington, you know, getting support for it not just from members of Congress but the whole civil rights community. Educating them about disability issues. They did become extremely supportive. Probably Mary Lou and Arlene in their interviews have talked about DREDF's beginnings and getting into that whole civil rights world in Washington, which is a fascinating story. But the upshot of it was that DREDF came to play a very prominent role in the Leadership Conference on Civil Rights [LCCR], which is this huge coalition of all the major civil rights organizations in the country. And they became totally educated, the LCCR, about disability issues from Pat and others at DREDF. Pat's been on their executive committee. It got to a point where DREDF and disability were included in any civil rights initiative, at the national level.

Jacobson: So was that one of the sustaining aspects of DREDF?

Lipton: Yes, it was, because in a very short period of time, through sheer persistence—they did, there were some strategic things that DREDF did in the early eighties, to kind of position itself to get recognized as a major disability national organization. I wasn't involved in this at all because this is when I was kind of really immersed in law school. But they held a conference out here and invited all of the hot shots from the civil rights community to come to California to advise DREDF on how to build a legal defense fund. The other side of it was, though, was a major educating process of teaching the civil rights lawyers and other leaders about disability issues. Basically explaining why disability is also a civil rights issue.

To prepare for that conference, DREDF wrote some incredibly wonderful, excellent papers on these issues—on the history of discrimination in employment and education—borrowing from all the civil rights, you know, *Brown v. Board of Education*, and all of the civil rights cases and the civil rights thinking in this country, so that this conference served two purposes. One was to educate the civil rights community, and the other was to get to know the civil rights community and get their advice on how to proceed. The big advice they had was for DREDF to get to Washington. Open an office in Washington. That you can't be a player there until you're there and so DREDF did that. And so it was, as I say, it was strategic because the early founders of DREDF knew what the purpose was, what the goals were, and wanted the support of the civil rights community. DREDF wanted their advice, you know, to benefit from their advice and their experience.

Jacobson: I want to ask you to go back to law school. Was your focus on learning about disability and the law?

Lipton: Well, they didn't have any classes on disability and the law. At that time. And I don't know, a lot of law schools do now. But at that time they didn't, mine didn't. So the only thing I really focused on was constitutional law and I did take whatever related

kinds of classes I could. Like there was one on employment discrimination. But none of those were focused on disability. So law school, much of it didn't seem very relevant to me, to what I wanted to do. I see in retrospect that's not totally true, because you do have to learn civil procedure, and there are a lot of things you need to know. But I didn't know at the time I might need to know them, but I knew what I wanted to do when I got out, and that was to do disability law.

History and revision of the Individuals with Disabilities Education Act, 1975-1997

Jacobson: Okay. We talked about DREDF and the ADA. What about DREDF and IDEA? And first of all, what is IDEA?

Lipton: IDEA is the Individuals with Disabilities Education Act. It's the federal law that guarantees every child who fits the definition of disability under the law of having a disability under that law, it guarantees them to the right to a free, appropriate public education in the least restrictive environment. And it was passed in '75. The regulations came out in '77. And it's a very, very comprehensive—

Jacobson: Was it a part of 504?

Lipton: It wasn't a part of 504, but the regulations, in particular, and the concepts of integration, were very, very similar. The 504 regulations that deal with education, which are very brief—primary and secondary education—use much of the same language as IDEA. It guarantees kids with disabilities who fit the definition of disability under 504, which is a broader definition than IDEA, the right to a free, appropriate education in the least restrictive environment.

The difference between the two is that IDEA has different eligibility criteria. Anyone with any disability who fits the 504-ADA definition, whether or not they need special education, is covered by 504. With IDEA, you have to have—it's a little narrower definition, because you have to have one of a laundry list of disabilities, and because of that, need special education. So there's a difference in who's eligible. And IDEA is much more comprehensive and detailed about the rights of children, of parents, of what kinds of individual education plans each child has to have, and how those are supposed to be developed and reviewed and revised. It's much, much more comprehensive, but has the same, really the same concepts.

Jacobson: And you probably know IDEA backward and forward.

Lipton: I do. I do. I know it. Yes, there have been amendments to it over the years, but the most significant amendments were in 1997, in [President Bill] Clinton's administration when Judy was assistant secretary.

Jacobson: Judy Heumann.

Lipton: Judy Heumann, while she was assistant secretary [of education]. Up until 1990, or 1992, the amendments were not—they didn't try to change anything of substance in the

law. There were things that were added to it, like educating kids at younger ages. And there was something added about transition from high school to post high school life, and how that was supposed to be addressed in individual education plans. But there were no real changes to anything core to the law until Judy came.

Jacobson: Then did you have any input about what went into those amendments?

Lipton: Yes, we did. We had a lot of input into it. Actually, a lot of people and a lot of groups representing a lot of interests had a lot of input into it.

Jacobson: What were the groups?

Lipton: Oh, there were all these administrator organizations. School board associations, principals, unions. Let's see, oh, you know, special education administrators, organizations, really, the whole gamut of organizations that represent school boards, administrators, teachers, other specialists, the speech therapy association, zillions of organizations, had a big stake in any changes that would be made to the law. And in addition to that, of course, there was disability and parent organizations, and other advocacy organizations that represent families and kids.

And it got very contentious, because there was this big, I mean, there were a lot of things in the law that weren't changed, but were kind of clarified and strengthened. Because there was always the requirement that kids be educated in the least restrictive environment, but there were things added to the law that really changed, that really emphasized that much more strongly, or made it clearer what that meant, and so forth. And there were other changes made to a lot of it. Not, again, none of the central core rights were changed. If anything, there were some things that were added to give parents additional rights.

But the big area of contention was over discipline, because under the IDEA, a child cannot be, could not be, under the old IDEA, could not be expelled or disciplined in some other way, if, for example, if their misbehavior, whatever they did, was related to their disability because basically, then, you're punishing the child because of the disability. And you should be addressing the child's problems, not punishing them.

And there were mechanisms in the law for dealing with emergency situations. Usually parents would agree to a change in placement if the school thought a child was dangerous or threatening in some way. And parents could challenge that in a due process hearing. In the meantime, the child had a right to stay where they were. It's called "stay put."

But the school districts could—and they did—could go to court, like in half a day, to get an injunction, a restraining order injunction, saying, you know, "This child is dangerous," and "we basically want you, judge, to let us bypass these other due process procedures to make a change in placement" or whatever. So there were ways that school districts could deal with a variety of discipline issues in the law.

But it was a time, and it started in the early nineties, more school violence became a huge issue, and disabled kids were a good target to blame for this increase in school violence. There was this very big movement in Congress, by Republicans, Trent Lott was among them, and many others [John] Ashcroft, who's now the attorney general. He offered several amendments to water down the rights of disabled kids greatly.

Economics, attitudes, and expectations impacting pre-1997 IDEA

[Tape 7, Side B]

Jacobson: Okay, I want to clarify that when we talk about people with disabilities, we're talking about a wide range of disabilities. Anything from physical to cognitive to learning disability.

Lipton: Right. And emotionally disabled. It's a very broad group of children with a broad variety of disabilities.

Jacobson: What were Lott and Ashcroft—

Lipton: And Gordon, Senator Gordon from Washington, was another one. What their position was is that kids with disabilities should be treated like everybody else and there shouldn't be a standard for some kids that was different from others.

Jacobson: Okay.

Lipton: Of course, what that doesn't address is the fact that kids have disabilities that affect their behavior for a whole variety of reasons. Or even that if a child is not getting an appropriate education, that that has an effect on, you know, if they're not getting the right services, they're not being taught anything. They're failing in school because their problems aren't getting addressed, that can cause behavior problems, too. And there were early drafts of amendments which would have even excluded kids with, you would have been able to punish kids with Tourette's, or who had seizures, because it was so loose what these amendments, the behavior, they were trying to address or deal with. So what these amendments tried to do is—basically, there's a whole bunch of rights kids have under IDEA to make sure they're not being disciplined for the wrong reasons. If the disability is unrelated to their misbehavior, they could be subject to the same, to expulsion, and so forth.

Jacobson: Could you give me an example?

Lipton: Yes. We had a case at that time of a boy who was in junior high school, an African American boy, student, who was in junior high. He had just moved back to the area where he lived. He'd been living in L.A. with his father for a couple of years and had come back to his original district in northern California. None of his school records came with him, or they claim they didn't get them. And his records would have clearly shown that he was a special ed student getting special ed services.

Well, when he came back to northern California, and re-enrolled in the schools he'd been in previously, the same school district, they didn't provide him with any special education, and he had very severe learning disabilities and emotional problems. So he was getting into trouble with other kids and around the middle of that year, or January or February, he got into a fight with another boy. Nobody was hurt, and I don't remember the details of the fight. But at any rate, nobody was hurt.

And next thing his mother knew was that they were up for an expulsion hearing before the school board, or representatives of the school board. She explained to them in the best way she could that he was a resource student. And I don't know that even the people who were hearing his expulsion hearing knew what that meant. She didn't explain very well what it was, but they ignored the information, and they expelled him from school.

And so, at that point she called us, and we looked at the whole situation and saw there were a whole bunch of procedures that they didn't follow. That he was a special education student. They were subject to IDEA. And we went to court to file for a TRO and a preliminary injunction to get him back into school immediately. He also was not a kid with any history of violent behavior. And the fight was, sounded really quite minor. And, I mean, compared to fights kids have in school.

So when we went to court to file these papers, the judge asked if we could, if the school district and us could talk and see if we could work this out. It was so clear that they had screwed up right from the beginning, and not providing him anything, that we were able to negotiate to get him back into school and to get him mental health services, to get him other services to address his learning disabilities, a whole array of services, which he should have been having years before, that he never got.

But one thing that was particularly interesting and eye opening to me about it, this was in the, I guess this was in the late eighties, or '87 or something, or '88, was I went, after the school district agreed that he could come back to school and they would forget about the expulsion, we had an IEP meeting. That's a meeting where, for each child, an individualized education plan is developed. It describes their strengths and their weaknesses and what services they need to address it and so forth and once that's written in this document, then the school has to provide whatever is in the document. And it's developed by an IEP team which includes the parents, and teachers and administrators, and other kind of relevant people.

At any rate, at that meeting, what was really interesting to me was that they started to talk about why they hadn't noticed that he might need special education. He had been there for six, seven months. And they said to the mother, I mean, the mother asked them, "Well, didn't you notice something?" She's very with it in her own way. And they said, "Well, he was getting Cs and Ds and only one F." Or something like that. "And mostly Ds," I think it was. And an F and maybe one C. And it was so apparent to me that if it had been a white, middle-class child, getting grades like that, somebody would have looked into something. But the expectations were so low. It was like, well, you know, Ds, it's sort of passing. And I said that at the meeting, you know, "If you were sitting here with a middle-class, white parent, you would not say that Cs and Ds and an F are acceptable grades. And you'd want to know why the student wasn't doing better." So, anyway, that was—

Jacobson: How did they react to that?

Lipton: They kind of didn't say much, actually. The subject sort of got changed. Well, like, "Could we go back, now, to how much speech therapy he might need?" They didn't want to really, I mean, there was nothing they could really say, except "Oh, yes, we consider Cs and Ds and Fs good for any kid." So I was, in a way, I was more outspoken in those years. I'd really say what I thought was going on in those meetings, because those meetings really can be so awful.

It's much easier to go to court and have a court hearing where there's a judge and there are rules of how you can behave, and who gets to talk when. At these meetings, IEP meetings, can get so contentious and so, there's so much aggression and anger on everybody's side that they're incredibly stressful. Obviously, particularly when the parents have a view of their child, or want certain services that the school district won't provide or doesn't agree with.

Jacobson: Is that mainly due to the fact of economics, that it will cost more?

Lipton: Yes, definitely. I mean, money is a huge factor, because there is a constant pressure on the schools to keep costs down. They don't have enough money, I mean, public schools, to educate anyone really well in this state. California used to many, many years ago. Now it's near last in per student spending. New York, for example, spends about almost nine thousand dollars per year on just, you know, per child. California spends about five thousand. But that's not the only reason.

Jacobson: Is that because of Prop. 13?

Lipton: It's largely because of Prop. 13. Yes, because that really affected public funding of public schools. But it's not only that. It's really, I mean, there could be a much bigger commitment in California, to fund public education adequately. Until this energy crisis, there was this big surplus we thought we had. And they still weren't going to, they were increasing money to schools, but not nearly to the extent that it needed to be. But it's not only money that was, especially in the earlier days, that was the issue. A lot of it was attitudinal. And expectations.

I think a lot of administrators themselves didn't know disabled people. They didn't know what was possible for a lot of kids with disabilities. They had no idea of the range of independent living that was possible. Or anything. They had no, kind of, real vision of where these kids could go. They had a lot of their own biases and prejudices, and those got played out in these meetings. And they still do. So even where money wasn't an issue, for example, like in the early days when integration consisted of taking kids from a special day class to a regular class for art or music, things that were not big ticket financial items, they still objected in those days. So it wasn't just money. It was also attitude and very low expectations for a lot of the kids. And the new IDEA tries to address those kinds of things.

Jacobson: Doesn't that make you wonder about, I don't quite know how to ask this, but the people you know now with disabilities, like Judy, like Neil [Jacobson], like me, doesn't it make you wonder how we got that education to get us where we are? Do you have any thoughts about that?

Lipton: Well, yes. I mean, for the people with disabilities who are now in their forties, fifties, and so forth, the people who I've met who have done well in terms of getting education and good jobs and things like that, seem to have had parents who, many of them seem to have parents who are very strong advocates. They're also very bright and able to demonstrate to the world that they were bright. And had spunk and whatever it takes to get through a system which is essentially hostile to them. That's the only way I can explain it.

I think there are probably zillions of others who didn't do so well because they didn't have the parents pushing, they weren't able to communicate who they are and what they could do very well. It's kind of a miracle that anyone, considering the terrible education, that I know Judy and Neil, and others received, wasn't much, for many years.

On the other hand, some people may have also had a couple of good teachers here and there who recognized their ability and who taught them something. But, you know, that's, I think it was really a handful of people. I think there were probably kids who went to blind schools for blind kids and deaf kids who probably got somewhat better services, also. Not that they've been able to fare so well in the job market or in higher education, either. So I don't know. I think it's miraculous, really, given how little you all got.

IDEA: an ideal law not well-implemented

Jacobson: And do you think that having the IEP and having IDEA is helping as much as it can?

Lipton: No. Not at all. Because, see, I think IDEA is a great model of how all education should be for every kid. I mean, ideally, every child should have an education plan that takes into account their strengths and their weaknesses and finds ways to let the child develop in their areas of weakness and utilize their areas of strength and all of that. But that's not going to happen in our lifetime. But I think the model of the law is excellent. I think the rights in the law are excellent. I mean, there are very important civil rights embodied in the law. The right to have an appropriate public education. There was no federal right for that before, and it was up to each state to do whatever they wanted for disabled kids. That's why the law came into being in the first place, because many kids were excluded entirely from schools. Kids with behavior problems, emotional problems, mental retardation, multiple disabilities, just didn't have any schooling.

And then parents started to bring lawsuits. There were about twenty-six lawsuits going on in the early seventies in different states, parent organizations using the U.S. constitution's equal protection arguments to litigate the right to a public education for kids with disabilities. And that was what precipitated the federal government passing a law.

Jacobson: Now, could you tell me—

Lipton: I just want to say, in answer to the question, the problem with the law is not the law itself. It's that it's not implemented properly. If it were implemented properly and the law was enforced the way it should be, I think we would see much more success for the kids. But implementation is the huge, big issue now.

Jacobson: Why is that such a big stumbling block?

Lipton: Well, again, money is a big reason. The schools are hurting so much generally that special ed is just going to feel the same financial problems. So that's a big, that's a very big issue. Other issues involve like training for teachers. For example, general education teachers, in their training, they get very, very little, if any, training on how to work with kids with diverse learning needs. Even kids who aren't disabled have diverse learning needs. And kids with disabilities add to it. They're completely untrained in how to work with those kids. So it's hard to—and then, there are other reasons. Special ed systems are kind of viewed as a separate system from regular education in school districts. And you know, the separate systems and separate administrations hasn't helped, either. There are a whole variety of reasons.

Jacobson: Who is responsible for addressing those issues?

Lipton: Well, at the local level it's the superintendent of each school district, ultimately [who] has the responsibility for making sure that their school district is following all the rules. And then beyond the local school district, the state department of education, here the California Department of Education, is supposed to be monitoring that every school district is doing what they're supposed to be doing. And then the federal government monitors the states to make sure that the states are doing what they should be doing, which includes monitoring the school districts, so there is this layer of supposed accountability.

Jacobson: Would that address the issue that the teachers, or the students that are going to be teachers, are getting the education they need to work with those students?

Lipton: Well, that's another whole issue, because there have been some changes in California on the teacher training requirements. And I think now when you get a general education teaching credential you have to have taken something in disability, but I think it's like only one course.

To compound it, we have a huge teacher shortage in California. Well, there is nationally, but it's very acute in California, the teacher shortage. So they're now looking, the legislature is looking for ways to cut back on requirements to get your teaching credential. To be a special ed teacher, you had to have a regular credential and another year or so of training, which was why a lot of people think teachers got turned off from going into special ed. Because it could be a two or three year post college graduate program.

But in general, the movement in the legislatures are now to cut back on the requirements, make it easier to become a teacher, to address the teacher shortage. So I don't know at what point the actual training of new, young teachers on how to work with kids with disabilities, is ever going to be what it should be. Many teachers wouldn't mind working with kids with disabilities, but they don't feel adequate to it. They don't feel like they know what to do. And they do need more support in classrooms.

— 64 —

Especially in, you know, you have a big urban classroom with thirty, thirty-five kids in it. You may have kids who speak a variety of languages, who have a big range of learning needs. Then you add kids with even more intensive learning needs, and behavior problems. It's pretty overwhelming for teachers, so they don't get the support, they don't get the training, they don't get what it really takes to be able to work with all these kids. They don't have small enough classrooms. It's a very complicated issue, why the law isn't being implemented the way it should be, and all of these factors enter into it.

One thing I wanted to add to the question earlier about the IEP meetings, and the fights between parents and administrators. There's another factor that enters into it. And this was very true in the early days when the law was passed, and it's still true today. School administrators were not used to sharing decision making with parents, and that was very uncomfortable, and it still is for a lot of administrators to deal with. The fact that they're supposed to be listening to parents. They're supposed to be taking the parents' concerns into consideration. The parents are supposed to actually help develop this education plan. And that sharing of power with parents, ultimately the school has all the power. They can just say no.

And then it's up to the parent to have to go through a very legalistic, due process procedure, to have the school district's decisions overturned. So ultimately it's the person with the pen at the meeting, which is the school administrator, who decides what gets written on that paper. But basically it's supposed to be a team approach. And administrators really were very hostile.

I mean, I went to my daughter's IEP meetings and other kids' IEP meetings in the late seventies, early eighties. They were not interested in what parents thought. You weren't always treated with a great deal of respect. You were made to feel like you had unrealistic expectations, and that we didn't understand the problems of the schools. And it could get quite, really difficult. Those meetings can be a nightmare for parents. When it works well, the law, it's great, when there really is this team approach, and when there really is a commitment to really try to give the kid what the child needs. It can be extremely positive.

Identifying children with special education needs

Jacobson: Have you seen it work well?

Lipton: I have seen it work well. We get called, of course, when things aren't working well. But I have seen it work well. You know, where people are really working together and there is a commitment to the child and to doing what's really going to help the child. And you see the benefits of it. You know, the child does better. It's not rocket science to figure that out. And overall, kids in special ed are doing better. You know, more kids are going on to higher education and so forth, but not nearly in the numbers that it should be.

— 65 —

And the California Department of Ed, for the first time, is collecting certain kinds of data, like how many kids from each district are graduating with a high school diploma, special ed students. And this just came out this last week. These are called key performance indicators. I was on some task force to develop these. And the department of ed here is going to use these as part of their monitoring process of school districts.

But what the data shows that they've just put on the Web this week with a big press release telling everybody don't take this too seriously, because we don't know how accurate this all is, we'll show in some school districts, like in Palo Alto, eighty percent of the special ed kids there graduate with a regular high school diploma. As opposed to, I think it was in Palos Verdes, or some other school district, where, like one percent were graduating with a high school diploma. And the rest of the kids, many of them, were getting GEDs, which is not really the same. Or a certificate, which is not the same. So the disparity that's going on through the state in these percentages, something is not going right.

Jacobson: And then you wonder about all the kids not in special ed that do poorly in school who are written off for one reason or another.

Lipton: Exactly right.

Jacobson: Who are not identified as having special needs and therefore, do not get services.

Lipton: Right. There's a huge group of kids like that. I just read something, I think in the paper, that 67 percent, only 67 percent of kids who start high school actually graduate, in California. That's pretty low. I mean, that's of all kids. I think it was 67 percent. So what happens to this other 33 percent? That's like a third of high school kids never graduate.

Jacobson: And so if a child is doing poorly in school, who is the one to report that? Is the teacher the one who is relied on to come out and say, "I think this kid might have a disability." Who—

[Tape 8, Side A]

Jacobson: Okay, so there's supposed to be this thing called child [inaudible].

Lipton: Right. What it means is that the school districts have an affirmative obligation to seek out the kids who may need some special ed services. The way it actually works is that a teacher—a child could be not doing well in school for a variety of reasons, having a disability is only one of them. But at any rate, when the teacher suspects that the child is not doing well because there might be some disability, a learning disability or emotional stuff that's getting in the way, or whatever, they can refer the child to the district psychologist to evaluate the child.

For kids in general, what schools now have are things that are called student study teams, where teachers can bring to a team sort of a multi-disciplinary team in the school, the children who are having difficulties in school. This team would then often decide that this kid needs to be referred for special ed evaluation. If there are other things that could be happening in the classroom to help the child succeed. So sometimes the referrals come via this student study team at the local school level, but parents can also request an evaluation if they think that their child might have a disability. It really could come from anybody in the schools who knows the child or the family. But, often teachers are discouraged from referring kids for evaluations for special ed, because the school districts have what they think are too many kids in special ed. It's to keep the cost down.

Jacobson: But doesn't the school district get extra money if they have a child who needs special ed?

Lipton: Yes, they do get. They get extra money from the federal money that comes with IDEA. IDEA is what's called a grant-in-aid statute. If the school district wants federal money, they have to comply with the law. I mean, if a state wants federal money, then the state has to be in compliance to the federal law. And all states take federal money. Because if they didn't want to comply with the law, they could just say, "Screw you, federal government. We don't want your money." And of course they would be subject, still, to [section] 504, which is what happened originally in New Mexico. But the point is that—what was your question?

Jacobson: Doesn't the school district—

Lipton: Yes, they do get extra money for special ed, but they're always complaining that the amount of extra money they get doesn't nearly cover the costs of educating kids with disabilities, and so they, then, use this term "encroachment." It's a word parents loathe. What they'll say is that special ed is encroaching on their general fund. And they have this notion, administrators and school boards, that somehow disabled kids are not the school's responsibility. The school district's responsibility—that the state, or the feds should be, you know, paying all the costs to educate these kids. Where in fact, why shouldn't the general education fund be used for their education, supplemented by what additional money they get. So this is kind of another area of disagreement. But there isn't enough, I mean, the reality is, is that the schools do need more money. They need money for all kids.

Jacobson: I bet that's why teachers are discouraged to report—

Lipton: Yes. I mean sometimes I've had teachers tell us very directly that they were told, "Don't refer kids for special ed." Or, "We have a year waiting list for evaluations," which is completely illegal. They're supposed to do them basically within thirty days of a referral, and within fifty days have done the evaluation and developed an IEP if the child turns out to be eligible for special ed services.

But the teachers are told very directly in many cases. Sometimes it's more subtle. And sometimes when they do refer, they see that nothing happens for so long, or ever, that it discourages them. They figure it's not going to happen, why bother. Sometimes a teacher will tell a parent, you know, "I think your kid needs special ed, and we need to get an evaluation," and the teacher and the parent kind of work together to make it happen. But that's not the case for most kids.

It's just teachers can't rely on parents pushing it, necessarily. Some parents don't want to hear it. Some just don't have the resources, emotionally, socially, financially, to stand

up to the school district and feel like they have a right to demand anything. It's very complicated. So the impact of this is that a lot of kids don't get referred.

Now on the other side of it is the whole issue of over-identification, particularly of minority kids. And historically, special ed has been a way to sort of get rid of kids who are pains in the neck, and it happens to be, for one reason or another. And sometimes, for example, more African American kids get identified as mentally retarded than as learning disabled. For white kids, it's the opposite. And there are a lot of protections in the evaluation procedures in the law to try to make sure there aren't discriminatory practices going on. In California, for example, they cannot use, under a court order, cannot use traditional IQ tests to test African American kids, because they've been shown, those tests, to be discriminatory. So there are two different problems. There's the under-identification, often, of kids with disabilities, because the school doesn't want to go over a certain number of kids getting special ed services. And then there's the over-identification, mostly of minority kids, as a way for teachers to not have to deal with their learning issues. So it's complicated, the whole—and the Office of Civil Rights, and other federal and state agencies, have been studying these issues for years. And there's no simple answer.

Calls to DREDF; consciousness raised by the ADA [Americans with Disabilities Act]

Jacobson: When do they call you?

Lipton: Parents?

Jacobson: Yes. When does DREDF get called?

Lipton: We usually get, we get a few thousand calls a year from parents, mostly in the Bay Area and throughout California, and from all over the country. We usually get called when there's a problem. We often get calls about discipline issues. Kids are being suspended over and over and over and no behavioral assessment has been done. No mental health assessment has been done. And the kid's on the verge of getting kicked out of school. That's one common scenario.

Another is just the child has, let's say, severe learning disabilities, and they're getting almost no services, which is very common. They'll go to some resource room for, like, a period a day, where mostly the kids sit and do homework, if they do anything. They don't get, in most of those resource rooms, they really don't get any of the attention they need from a resource specialist. Or they'll have an aide in the room. Occasionally that won't be true and there will be something with more substance going on, but often it's just a place where a kid goes to do their homework. Meantime, they're missing some other general ed class.

I just talked to a mother yesterday whose son, actually, he has Asperger Syndrome. And he's a very, very bright kid, but socially he has some real deficits. And he's at UC Davis studying engineering. Well, when he was in high school, at the beginning of high school, he was being pulled out to the resource room, missing math and science, which were his two best subjects and so, at some point, his parents said, "No more of this special ed because he's not getting what he needs in the areas he needs," and he was missing out on the areas that he was good at.

Anyway, so that's the kind of thing. Parents will call and just say their kid's doing poorly, and nobody's doing anything about it. Or their kid is too segregated, and they want them in a regular class. They're not having access to the general curriculum. It's just a range of subjects. And usually they call after they've been around with the school district on the problem, where they've already been arguing and pushing as much as they can. So they call us, they're very frustrated, very upset, and they don't know what to do next, what their rights are, sometimes. Or they need to just talk about their frustration and get some ideas about how to proceed.

Jacobson: Tell me about—

Lipton: One thing I do want to mention, I don't know if I mentioned this earlier. The calls that we get now are very different, in certain ways, from calls we got ten years ago. For example, there is a much greater expectation of parents right now that their kids are going to be in regular classes. We, my generation of parents, we didn't have those expectations. And it's a wonderful thing. Because it should be that way. And it's a number of things which have changed the consciousness of parents. You know, the ADA. Even if they don't know there's an ADA, they see the handicapped signs in parking lots, and there's just a change in consciousness. They hear about kids with disabilities in regular schools and regular classes. And parents of young kids have a completely different expectation from the expectations we had. We were just grateful if the school took our kids in anything and that's not true, now. Not with the calls we get, anyway. Parents, for the most part, really want their kids integrated into regular classes, but with good services.

Holland versus East Palo Alto

Jacobson: Tell me about Holland versus East Palo Alto.

Lipton: Oh. Well, the Hollands, that family, is a good example of what I was just talking about. That case litigated the right of a—Rachel Holland, who, I think she was seven at the time when this all started. Her parents wanted her in a regular—initially, it started before that. They were trying to get her in a regular kindergarten class. And because she was in this special preschool and special kindergarten, and they noticed that it was a very big difference between the special ed kindergarten and the regular kindergarten—which were next door to each other—and the special ed kids—what went on there, was that they were being taught, or made, to sit still in a chair and sit at a table. And that was a lot of what was going on in that class, that they had to sit there. There weren't the variety of materials. There was nothing on the walls. There was like, the special ed class looked totally different from the regular kindergarten class where you'd go in and there was a lot of bustle of activity, and kids doing a variety of things, and moving from

table to table, and having beautiful, in this particular school, had very nice materials, and everything.

So finally, the Hollands—Rachel has a developmental disability. The school district kept talking about how she has an IQ of forty-four. They said that publicly about a hundred million times. But Rachel had also gone to, she's a very lovable, social kid, and she'd been going to a Jewish preschool earlier on. And to a day camp that this, their congregation ran, and she did fine. And she loved being around the other kids, and she would try to do what everyone else was doing.

Her parents saw that, versus this special ed class, which looked so depressing. Just walking into the room was depressing. And the goals were totally inappropriate for any kid that age. So they started a press to get her at least to go to the kindergarten some of the day. The school district gave them a really hard time about that, and agreed to do some of it, and never did it. And it was just going badly. This was a two year battle.

Finally the parents just said they had enough. They didn't want her in this special day class at all anymore. They wanted her in that regular kindergarten. In a regular kindergarten. And they went through due process hearing. They took her out of the public school. And this Jewish private school where they had been, where she had done some, like nursery school, preschool kinds of stuff, agreed to take Rachel. Her parents hired someone who knew about integration, and how to integrate her, to do a little bit of consulting with the regular teacher. And the year went great.

During this time, there were mediation sessions with the school district, and a hearing going on, and the people from the private school came and testified that she did fine. The teacher said her only regret was that she didn't have time to give the little extra time Rachel could have used from a teacher. She felt badly about that. But she said other than that, she thought she fit in fine, the kids accepted her fine, she learned a lot, and imitated what the other kids were doing.

So we won that hearing, that administrative hearing. The school district appealed it to federal court. Federal district court. We had another short trial, evidentiary hearing, in federal court, where now her first grade teacher came and testified in court, who was amazing. She talked about how she'd never really worked with any disabled child and was scared about it at first. She said mostly if she'd be able to meet her needs, and she told these stories of how, what a wonderful experience it was, having Rachel in her class. For Rachel and for the other kids. And she's one of these teachers, I think this was second grade by this time, that you'd die to have your kids in her class. She was like the archetype of a wonderful second grade teacher. She said that Rachel's goals and objectives—Rachel wasn't reading quite at the same level, or doing math, as other kids, and so forth—but what the teacher said is that the real goal in second grade was to socialize the kids, develop their language skills and their social skills—learn how to interact with other people and children. And she said those are exactly the same goals that Rachel has. She said, "We're not teaching nuclear physics here," that kind of thing.

She told these very touching stories about Rachel's participation, and the other kids loving Rachel, and that that's where she belonged, in her opinion. We had other experts and blah, blah, blah, testify. And the school district looked like the meanest people in the world. They were talking about how Rachel came to school inappropriately dressed because she was wearing black pants and a black shirt. They talked about, they just were just off the wall. I mean, it was disgraceful, the things they said.

What was so fascinating was the different views of the same thing Rachel did, because the school district came to observe her in the private school, and the parents' experts observed her in the private school. And both experts were there at the same time, observed the same incident: Rachel was walking outside with a couple of kids near her and she saw a piece of paper on the ground. She picked the paper up, and she threw it in the trash can. To the school district expert, that meant that she couldn't sustain the interaction with the kids. You know, that she was just off doing her own thing. And to the other expert, it meant Rachel noticed this was there, she picked it up, it was a totally appropriate thing for her or any of the kids to have done at that particular moment.

So the trial was so interesting because you had completely conflicting views of how Rachel was seen. Most of the people in the school district side were these old fuddy duds who'd never seen kids really integrated. And on our side, we had these young, university types who just, you know, just had no question—of course she can be in this class! This is where she's going to learn. They talked about how she's motivated, what motivates her, and all of these things.

We got a very good decision from this judge in which he really laid out the factors that you use. What the law says is that every child with a disability has the right to be educated with children who are not disabled. Unless, in regular classes, unless they cannot achieve—with supplementary aids and services—unless they cannot achieve satisfactorily in the regular class.

So the presumption is in the law in favor of placing a kid in regular classes with supplementary aids and services. It doesn't mean you have to do that with every child. But that's the presumption. That's where you start from. And so what the court did was analyze, well, how do you determine if a child can get a satisfactory education with supplementary aids and services, in a regular class? And he laid out the relevant factors, and those relevant factors have become the standard for the ninth circuit.

The school district appealed that decision to the ninth circuit, the court of appeals. The court of appeals affirmed, agreed with the district court. And that court of appeals covers a bunch of states, like Arizona, New Mexico, I believe, California, Oregon, Washington, Hawaii. And so that's the law in these states. The school district tried to appeal it to the US Supreme Court. And fortunately, because the court, this was in '94, was it? '94, or '92? God, I'm forgetting now. Anyway, in the early nineties. The Supreme Court declined to hear the case, and one reason may have been because there were two or three other decisions in other courts of appeals around the country that were pretty consistent with the one here in California.

So there wasn't a big conflict among the courts, the federal courts. So there may have been other political reasons why they didn't want to take the case. You don't know. So that let stand the court of appeals decision. That case has had an enormous impact on the right of kids with disabilities to be in regular classes with whatever support services they need, and it's really changed things in a pretty dramatic way.

— 71 —

IDEA amended to recover legal fees, 1992

Jacobson: Did Rachel eventually get into public school?

Lipton: Yes. She went into public school. What the school district was proposing, by the way, throughout this, was that she be in a special day class, but to go to the regular class for different activities through the day. The schedule that they presented was so preposterous. It was like she could go to home room, regular home room, for fifteen minutes. Then she had to go to the special ed class when the regular class was doing reading. Then, when they did music, she could come back to the regular class. And an aid would bring her back and forth. What they proposed was a schedule in which she was, like, moving back and forth six times a day. Literally. From one class to another class.

The judge immediately got, what kind of a young kid can cope with that, let alone a child with disabilities, for whom things might be a little bit more confusing, and his decision, this was the initial district court, Judge Levy, he really, totally got it. He's a very, very bright, scholarly judge. Not known as a big civil rights liberal judge. But he totally got it. And he said, in his decision, that this back and forth thing just would not provide the sense of belonging and being part of a classroom that seems to have been so beneficial for her. You know, this going back and forth he thought was ridiculous. That her having a sense of belonging to the class was very important in the way she functioned and in the way that other kids would view her. So it was a wonderful decision, because he totally got it, what the issues were, and so forth.

Anyway, all this litigation took about five years, six years, really, even longer, from the time they first started talking to the school district, when she was, like, three years old. Her parents were paying for the private school. At the end of it, they [the school district] had to reimburse the parents for a lot of the costs of the schooling. And the parents had to pay for an aid for awhile. It was a tremendous financial hardship for them, the family, but they were committed to it. They did get reimbursed for at least some of it, and for attorneys' fees.

That's, by the way, one thing that I'm very proud of DREDF about. Because in 1986, the original IDEA, which was called the Education for all Handicapped Children Act, was changed to be more politically correct in 1990. The name of the law. But it originally did not have an attorneys' fees provision, like other civil rights law do, which allow the plaintiff, in this case the parents, who win a case, to recover attorneys' fees from the other side—from the school district. There was no provision like that. Well, I think it was in 1986, there was a move to amend the law to include an attorneys' fees provision. But it wasn't going to cover administrative legal costs for administrative hearings, and for a couple of other things. When DREDF got involved, and this was Arlene's doing, when she saw the amendments that were being discussed, she went to Washington and told the disability community, and the parent community there, "You have to go beyond this amendment. This attorneys' fees provisions has to be the same as it is in other civil rights statutes, where you have the right to recover legal fees for going through administrative hearings, and other costs, and so forth." She had to convince our own community that they hadn't gone far enough, and that is, in fact, what happened. The amendment went the way Arlene was pushing it to go. It's the kind of

thing DREDF really does well, to be able to, its analysis of the issues, of what it should be, to come in and change language, to refine it to make sure that the civil rights of the kid are protected the way other people's civil rights are protected. So that was a big accomplishment which everybody, school districts, of course, hate.

Jacobson: I think this might be a good place to stop.

V. Personal and Professional Experience with Special Education Issues

Chloe's high school and transition program

[Interview 5: September 14, 2001] [Tape 9, Side A]

Jacobson: Let's get back to your family.

Lipton: My family?

Jacobson: Yes. I know that you married Jim. What year?

Lipton: In 1982.

Jacobson: So you've been married for nineteen years?

Lipton: Yes. Almost nineteen years.

Jacobson: And was Chloe living at home with you at that time?

Lipton: Yes. Yes, let's see how old she would have been. She was about nine or ten years old.

Jacobson: Okay. What were some of the issues she had going on in school?

Lipton: At that time?

Jacobson: Yes.

Lipton: I'm trying to remember. Let's see, at that time she was in elementary school. The biggest issue, I think, at that time was integration. She was in a special—by that time, all of the special schools in Richmond closed, and all of the classes from those schools were moved to regular schools. The big issue was trying to get the kids integrated with nondisabled kids, as much as possible. For me, that was the biggest issue at the time.

— 74 —

Jacobson: What kinds of things were you doing to make sure that that happened?

Lipton: Well, when she was around ten, eleven, she was in a school; it was called Lake School, I think, an elementary school in Richmond. She had a very, very nice teacher and aide, a very good teacher. The teacher, I know, was trying to work with some of the regular education teachers to have her kids, the special ed kids, more integrated, and going for more activities each day, to regular ed classes. There was a fair amount of resistance to it.

Jacobson: So was this special class a part of the public school?

Lipton: It was in the public elementary school in Richmond. It was in the school; it was not isolated off in the backyard of the school, the way—at that time, and still is—many elementary schools have portables. You usually found the special ed classes, or find them, in these portables, kind of at the other end of the playing field. [laughs] So, technically they are on the same school site as the regular school site, but the reality is, often, very often, physically they are pretty far removed. In this instance she wasn't.

The class, as I recall, was pretty much in the middle of the school. This was out of sort of a lot of lip service to having the special ed kids be part of the school. But it was very limited, the number of activities that she actually spent with regular education students. I can't remember precisely how much time, but I think it was, you know, maybe one activity a day or maybe two. Sometimes they were with different classes, and she never had the opportunity to develop relationships with any of the kids, which is really a lot of the point of integration. But the way they were doing integration didn't lend itself to that. I don't recall if at that time we were continuing to write administrative complaints about the situation or if we were trying to work more informally with the district administration and the teachers. So—.

Jacobson: It sounds like you had a constant, ongoing battle.

Lipton: It was. It was a constant, ongoing battle, until the day she left the school district at twenty-three, because each situation she went to had unique problems. The integration was a continuous problem. After she was at Lake School, she went to a junior high school, also in the Richmond school district. The principal there was actually extremely resistant to integration, and I believe we did write complaints against that principal to the Department of Education.

Jacobson: Was it just you, or—?

Lipton: No, there were a couple of other parents too. Again, the sort of saving grace for me personally, for Chloe, was that she had very good teachers, up until there was the one or two years at the junior high that were not very good; the teachers were not that competent. Most of the time she had very competent teachers. It wasn't until she got to high school, though, and she went to DeAnza High School in the Richmond school district—we had a lot of problems at the junior high, I remember that, with the principal. He was very resistant to integration. Then at the high school, at DeAnza High School, there were quite a few special ed classes, because they came from a couple of different junior highs. They were kind of all grouped together in one wing of the building, not totally isolated from the rest of the school, but a little bit. [laughs]

The one thing that was interesting there was that the teachers were this new crop of teachers—the special ed teachers—who had been recently trained, and very much trained in favor of integration and inclusion. It was different because the effort to integrate started to come as much from them as it did from parents. Previously, the special ed teachers, even the very competent teachers—and by competent I mean people who were smart, very conscientious—had a real structured approach to how they were teaching academic subjects, as well as independent living skills. There wasn't fooling around in the classroom. They took their job seriously, and there was a lot going on in the classroom, but the teachers, once Chloe was in high school, were more newly trained. Most of them came from San Francisco State University, which has a special ed department, particularly its credential program in working with severely disabled kids, which is extremely pro-integration. Some of the leaders in that nationally were at that university. So that was a real shift, because then we started to have teachers who—we didn't have to convince the teachers of the importance of it. And they were trying to do it by making contacts with other teachers, meeting with the principal, and sort of infiltrating the school as best they could.

Jacobson: So it took some of onus off you as a parent.

Lipton: Well, to some extent it did. On the other hand, the teachers relied a lot on the parents, in front of the administrators, to be the ones pushing for this.

Jacobson: What year was this?

Lipton: Well, let's see. I would say between the ages of maybe fifteen and nineteen, Chloe was at the high school. That's about ten to fourteen years ago. So what would fourteen years ago be, around 1987 or something. 1987 to '91, or something, '90? '91. Something like that. Then from 1991 or so, for the next three, almost four years, Chloe was in the district's transition program. That program—well, she stayed at the high school an extra year, because the transition program didn't look that hot to me. I thought what was happening at the high school, she was having some job training experiences, some integration with other high school kids, and again, with good teachers. The transition program seemed to me to be very segregated and not well organized, so I wasn't anxious for her to go into that. But she did finally go into that.

That program, part of the program that she was in, was located at the local community college, which is kind of ideal for that age group. However, they were completely isolated. The Richmond school district was given one or two classrooms there, with very little expectation that the kids in those classrooms would be taking classes on the campus. A few of what were referred to as the "higher functioning" kids were taking a couple of regular classes. I don't think they expected Chloe or many of the students to be doing that, and basically [they] were staying in this one classroom most of the day—not doing very much, I might add. So that was totally unacceptable, and the battle began all over again, because these teachers at the transition program had been with the district for a very long time, twenty, twenty-five years, and they sort of were comfortable in their little segregated enclave.

Involvement with amending IDEA, 1993-97

Jacobson: When did the transition program come into being, because I don't remember it existing earlier?

Lipton: Well, IDEA, the law, says that kids, according to their IEPs—their individual plan—who need to be educated beyond age eighteen, or the age they would normally graduate from high school, have a right to be in school until age twenty-two. In California that means until their twenty-third birthday. And it was optional to the states to provide education to that age, but California did. Then—and now all states—well, I think all states do have—but pretty much, it is the kids with severe and multiple disabilities who stay in those years, sort of the eighteen to twenty-two year old kids with more severe, multiple disabilities—and who are not going to be graduating with a regular high school diploma. I mean, there are many kids with learning disabilities who may not graduate either, but normally the districts don't have transition programs for them. Although legally, they have the same right to it, if their IEP team thinks it's necessary. However, a lot of kids that age don't want to stay in high school.

But in 1990 there were some amendments to the law that actually required transition planning, starting at age sixteen and required the school districts at the IEP meetings, to actually start a process of planning what every special ed student was going to be doing, projecting what they might be doing when they left school, and to start gathering the agencies and the resources to plan for the transition from school to post-school. The law was amended again in '97 to require that that planning process actually begin at age fourteen.

Jacobson: When was the law signed. What year?

Lipton: Originally the law was signed, it was called the Education for All Handicapped Children Act, in 1975. The regulations came out in '77 around the same time as the 504 regs came out. There is a lot of overlap in the language and in the requirements. Then, it had never been really substantially amended. Well, there were a few major amendments that happened in the late eighties regarding early intervention services for kids, from birth to three, and then these requirements regarding transition at the higher end, higher ages.

Jacobson: When did they become IDEA?

Lipton: It was either, let's see, 1990 or '92, the name of the law was actually changed.

Jacobson: To?

Lipton: To the Individuals with Disabilities Education Act, to make the language more politically correct. It is the same law. So I think it was in 1990, but again, it might have been '92. Then the law had its first amendment of a real substantive nature in '97, while Judy Heumann was the head of OSERS [Office of Special Education and Rehabilitation Services]. From 1993 to '97, it was four years of unbelievable strategizing, and drafts, and redrafts of the law, for the first time.

Jacobson: Were you involved?

Lipton: Yes, in DREDF I was extremely involved in this process. The reason it happened was, in the early nineties there was an increase in school violence and a lot of publicity regarding school violence. Members of Congress began to blame and scapegoat kids with disabilities as being the cause of a lot of the disruption or violence in schools. They began a campaign to change the parts of the law that gave kids with disabilities some additional protections from being suspended or expelled from school without services.

The reason they had more protections in the law is because when the law was written, there was first of all recognition that kids, the reason for the law in the first place is because so many kids, disabled kids, had been excluded from school for so-called "behavior problem" reasons. I mean, like thousands or millions of children throughout the United States. The law was designed to, rather than kick kids out and exclude them, to address those problems that the kids had. So there were some protections in the law to make it harder to just throw kids out of school because of a disability. But Congress in the nineties started to say, well, these protections went too far, and it basically meant you could never discipline special ed kids and kids who were violent or disruptive; the hands of the schools were tied to deal with these kids—that, in fact was not true.

I won't go into it now; there were mechanisms in the law to deal with dangerous or unsafe situations. But the reality of the law was ignored, and there was this huge campaign in Congress. One of the people who led it, by the way, was Senator [John] Ashcroft, who is now the attorney general. So the special ed community was very aware of who he was when he was nominated to be attorney general. The administration, which at the time was the Clinton administration, decided to deal with the issue proactively, by supporting opening up the law to amendment, and to strengthen parts of the law they thought needed to be strengthened, or clarified, and also to draft and make proposals regarding discipline that would be a lot less detrimental to kids than the proposals that were coming from the Republicans in Congress. So that began, whether or not that was a correct strategy, you know, people still debate, whether the administration should have taken that route. Parents at the time were saying that there was nothing wrong with the law, it needed no amendment, it needed to just be implemented properly, and that the schools had a lot of options and ways to deal with kids who presented behavior problems.

But at any rate, so there was four years of tremendous involvement and engagement of the parent community throughout the country. Advocacy organizations, the administration bringing forth drafts and proposals, and having to work with Congress, a very Republican Congress, especially after the '94 elections.

Other issues emerged besides this discipline one. A big one that was under attack was attorneys' fees, because the Republicans were opposed also to the provisions in the law which provides for the parents to be paid attorneys' fees by the school districts if the parents win in an administrative or court appeals, which is a very typical provision for civil rights laws. Almost all civil rights laws have—they're called "fee-shifting statutes," that if the plaintiff wins, the person alleging discrimination wins, the other side has to pay their attorneys' fees. That is to encourage people and give people resources to actually bring discrimination suits. You know, that is the policy behind it. That was really under attack. And there were some other very key provisions of the law

that were also under attack. The administration fortunately, because Judy—it was a Democratic administration, Judy was the head of OSERS—the Secretary of Education Riley had a lot of respect for Judy and her judgement. Some very good changes were made in the law. The core rights were not affected, but there were some things that were added to the law, which were very favorable to kids.

Jacobson: What was your role?

Lipton: Our [DREDF's] role was two-fold. One was, we worked with the administration a lot, the department of education, giving them a lot of input into drafts of the law, of the proposed changes, giving them our ideas. They were also getting input from all interested parties, not just from us as parents and advocates. They were meeting with administrators, with the unions. But we did have a lot of access to talking with them, informally, about our concerns about various proposals. We had a lot of credibility for two reasons. One was just that DREDF as an organization has had a very good track record of being able to work with Congress and the White House, and negotiate compromises or language in the law that has been quite protective of people with disabilities in the ADA, and during the whole ADA process, and so forth. The other was that we, DREDF, while we work on the national policy on the legislation front, and you know, appellate courts, and the Supreme Court, we also work kind of in the trenches by going to IEP meetings with parents, meeting with local school people. We really have a lot of credibility in terms of knowing how a change in policy actually will affect kids, because we work kind of both at this big national level and also at the level of representing one kid at their IEP meeting. [laughter] So we know really what changes in policy mean, what effect it is going to have. So I spent, during those years, a great deal of time talking with Judy, talking with her staff, informally just discussing what impact proposed changes, either coming from the department, or from Congress, or from other organizations—they were getting proposals from National School Boards Association, from various administrative groups, from everybody.

Then, we also worked a lot with members of Congress, you know, trying to understand what the concerns of Congress were, and think of creative ways to address their concerns without compromising the rights of children. So I and others at DREDF were very involved in many meetings in Washington with many different players, particularly on the discipline issue. We also provided, there is a National Parent Network in Washington. I talked to them a lot providing kind of legal backup to them, in terms of what the case law said on different issues, what the legal implications might be of various proposals, and so forth.

So during those years I was very involved in a number of different ways, with that process. It was amazing to think of how much time Congress and the department spent on this reauthorization for the first time; there had never been this amount of controversy. It got pretty ugly at times. I couldn't understand why Congress, certain members of Congress were so focused on this. It seemed like, you know, aren't there bigger issues that the country has to deal with? But it kind of went hand in hand with a lot of changes that were going on then, the expansion of the prisons, the kind of punitive, rather than rehabilitative approach—.

Jacobson: Let me turn the tape over.

Lipton: Okay.

The Jimmy Peters case

[Tape 9, Side B]

Jacobson: Diane, you were saying that it went along with their approach to prisons and—.

Lipton: Yes, I think the Congress that we were dealing with at the time was very focused on school violence, on crime generally, and you know, these became—these were political issues, and they weren't being approached from a, you know, "what makes good educational and social policy" perspective, in my mind, but more from a "what will get the votes?" There was a lot of irrationality to some of it. Now we are sort of seeing the consequences of it, the "three strikes you're out" kind of laws, you know, the kind of mandatory sentencing sort of laws. Now people are sort of rethinking some of that stuff, because of the expense, and also starting to question whether this is really good social policy for the country.

So we were sort of, "we" meaning the disability and special ed community, sort of got swept up into that political bandwagon. Disabled kids, as far as the school issues, safety issues went, were a good scapegoat. There was no data to support the contention that disabled kids were responsible for an increase in school violence and disruption. There were a lot of hearings, congressional hearings on the subject. The anecdotes that administrators came forward with in support of changing the law were based on the most, you know, exaggerated, or distorted situations.

One of them I was actually quite involved with. One of the cases that kept coming up in Congress at these hearings and so forth was the case of Jimmy Peters, who was a boy from southern California, an African American child and family living in white Orange County in southern California. Jimmy has some cognitive disabilities, difficulties communicating verbally, and some other disabilities. Well, his father was very in favor of inclusion and wanted him in regular classes with special ed support services. The district did that briefly down there and then wanted him out of the regular class. The father wouldn't agree to it, and the school district went to court. They could have gone to a hearing to have a special education hearing officer resolve the issue of an appropriate placement. But instead, the school district actually went to court to ask for, federal court, to ask for a restraining order, to allow them to move the kid where they wanted, without having to go through any of the procedures of IDEA. What they alleged was that the six year old kid was really dangerous, and had to be removed from the regular ed class. He would be okay in a special ed class, I guess, he wasn't going to be a danger to the disabled kids. What came out in the course of the hearing on the TRO [temporary restraining order] was that there were aides in the class that did a lot of provocative things. He wasn't allowed to eat chocolate or candy, chocolate I believe. The aide put a bowl of M&Ms on the table, and Jimmy would grab for it, the aide would try to take it out of his hand, and he wouldn't let go of it, and then he would, you know, hit the aide, and push her away. Those were the kinds of incidents that happened. The

judge was furious, because he basically said, "There is no evidence this six year old little boy is dangerous, and why are you even in my court here?"

Now, the lawyer who represented the district in the case went to Congress, went there many times. He was well financed by, I'm not sure who, the California School Board Association, or the National School Boards Association saying that they had this dangerous kid, Jimmy Peters, who, I don't know what he said he did, bit people, or—I don't know, he had no weapons. But he was dangerous, and they couldn't change his placement. I was able to go and testify at that same hearing because I began representing Jimmy at that time, right after that court hearing, to try and get an appropriate program and services for him. I could go to those hearings and say, "This is not true. We're talking about a six year old boy, who has some behavior problems, but he is not violent. If anything, the worry is more that he will wander off, than he will hurt people," and, you know, bring some reality of what these people are talking about.

Jacobson: How did you find out that the aides were provoking him?

Lipton: Because other aides in the room told his father what had happened. It became, that case, extremely ugly, because the teachers and the principals were telling other parents how dangerous this little boy was. He had his own aide, so, you know, there is no reason in the world why his behavior really should have been a problem—

Jacobson: Yes.

Lipton: —or certainly any danger to any other kid in the class. But after the district lost that in court, parents started picketing the school to get him out. I mean, and there was a lot of media there—it was really like some version of a lynching. And they are an African American family, and everyone else there was white, and the whole situation got very, very ugly. His father though, was really steadfast in his convictions. He is still battling with the school district to this day, and this was like eight years ago, seven or eight years ago. What was your question? [laughs]

Jacobson: I want to know how you were involved in—?

Lipton: At some point, well, the father called us—his father's name is Jim—right after this court thing happened, and he sent me copies of these newspaper clippings showing people picketing about, you know, "We don't want dangerous kids in our school," and he had to bring his kid to school in the middle of this. It was naturally a very compelling story. So we agreed to represent him and help him work out an appropriate program with the school district. We brought in some experts, behavior experts, and inclusion experts who are in that geographical area, who, you know, told us this is just absurd, that they can't deal with this child, and, you know, "We're ready to really work with the district, train some of the staff, show them how you develop a positive intervention plan, and how to implement it, how he could be included." We had really some of the best experts in the country who were nearby, and very willing to help, and came to meetings, and faced—not 100 percent, there were some staff that were more open than others—but pretty much it was big resistance. The school district was not interested in making it work.

Jacobson: So what finally happened?

Lipton: Finally what happened was, the father—they started to do kind of really nasty things, like coming to his home, and checking up on where he was living, and trying to allege that he wasn't living where he said was living, and coming at weird hours to check up on who was living in his apartment, and blah blah blah. At some point his father took him out of school and put him in a private school, because he was worried about how Jimmy would be treated in school when he wasn't around, when the father wasn't around, and didn't trust that he would be treated appropriately and well. The father then began to be an advocate for other parents, and he has been helping, for years, other parents, you know, get services, and so forth for their kids. So for a number of years Jimmy was in a private school, but it was not a really good situation for him. The father did not think it was such a great situation, but he was there, at least, because he felt his son was safe there. He tried to supplement—it was a private school that mainly worked with disabled kids—and tried to supplement it with other kinds of activities, where he would be integrated more. Now, in the last year, his father wants him—he is junior high school age now—his father wants him back in school, and he should be back in regular school. They are in the middle of hearings now, because the school still wants him put in special day class, special education class. It is the same issue. The father wants him integrated. So they are in the middle of hearings now. We are not representing him in the current round of hearings.

So the point of all of this, though, is that during the reauthorization, there were a lot of allegations made, again, by school board people, by administrators, that the law had to be changed, because they had all these violent kids that they were unable to get out of school, or to change their placement, because of all the stringent procedures in the law. I testified that, you know, A) the law did have procedures in it to deal with kids who were violent. For example, you could go to court, the school district, and get a TRO to change the kid's placement, to do anything the judge thought was right to do with the kid, on a day's notice. That's a restraining order.

But they could do other things short of—and by the way, the school districts all have lawyers, who could—you know, when you have like, papers that are boiler plate, you fill in the names, and you could be in court the next day if you wanted to. They had other options. Most of the time, it is just telling the parent, "We think that your kid should be in this other placement. This will be better for him or her." And 99 out of 100 times, the parents agree, because, for one thing, they agree either because they don't really understand they have a right to say no, or they agree that the kid is not getting along with the teacher, and it is best to move the child. There are a lot of reasons, but most of the time parents agree. Secondly, the school district could go through a hearing process, an administrative hearing process, without going to court to change the placement; when it's so dangerous that they can't keep the kid for another day in the same placement, they can go to court, and the judge can order the district to give them the right to do whatever they want. There aren't that many kids dangerous like that. Of course, if kids are caught with weapons, and other kinds of things, they can suspend kids for certain periods of time without any consequences [for the school district], and so forth.

So the law did contain ways to address these situations. But the school boards would come forward and tell Congress the law tied their hands, and there's nothing they can do. Then they'd present these stories, like Jimmy Peters. So it was very helpful to have

people like me, who intimately knew the facts of these cases to be able to come forward and say, "This is not accurate, and this in fact is—this is what happened."

Special ed and mental health issues

Jacobson: Now that we're talking about school violence—and it has escalated in recent years—I'm thinking about Columbine High School, and other parts of the country. I know that one question that comes up about the kids who come in with guns and attack is, are these kids the ones who should have been in special ed in the first place?

Lipton: Well, you know, it's hard to know, you know. By the way, almost none of them that I know of were special ed students. [laughter] But I am sure that with some of them, probably there were indications that these kids had some real serious mental health problems, and perhaps should have been identified as special ed, and should have been getting some mental health services. I don't know enough of the real facts of their backgrounds to know that. But—.

Jacobson: Is that something that DREDF would be looking into?

Lipton: Yes. Right now we're actually developing projects that focus on mental health issues, because one of the biggest problems, not only in California, but nationally, is the lack of mental health services for school-aged kids, even for kids identified as special ed because they are emotionally disturbed. The majority of those kids get very little, in many cases, no mental health services—even though that's why they are identified as special ed, and they may be in classes for emotionally disturbed kids, with teachers who have no training in working with those kids—and sometimes they only have emergency credentials, don't even have any special education training, let alone training in working with emotionally disturbed kids. In California the Department of Mental Health is supposed to work cooperatively with the local education agencies, and provide the mental health services required under IDEA, through some interagency agreements. The fact is that Mental Health operates totally separately. They don't have the staff to do it. The kids who may be getting therapy or services for mental health, which are the minority of the emotionally disturbed kids, there is no coordination between those services and what goes on all day in school. It just is a total mess, and everyone knows that there is this huge failure of the system to provide these services.

Jacobson: I guess, I want to qualify that, when you say minority, you're talking about numbers—

Lipton: Right, right.

Jacobson: —and not ethnic affiliation.

Lipton: Not race, ethnicity, no, no. I'm just talking about numbers, right.

Jacobson: Okay.

Lipton: Yes. So this is a huge problem, as I said, in California and elsewhere. As we said, we are in the process of developing—we've done some research on it, the numbers of kids receiving mental health services who need them are a very small percentage, maybe 5 or 10 percent. So we are developing projects now to address that. One of the things we would like to do is to work with disability and special ed, and mental health advocates to really design what we think should be a model system for providing those services. We've been looking at things going on around the country—but really come up with a statewide system that could really address the problems. It's going to be expensive and cost money.

Jacobson: Yes.

Lipton: So the question is, do we put the money in now, or do we put them in later, in prisons? Because it is pretty much a straight shot, we know that from emotionally-disturbed, behaviorally-disturbed kids, who don't get their problems addressed early on, they are going to pass go and go right to jail, and we know that statistically.

Jacobson: It sounds like a very appropriate way to start to address those kinds of issues.

Lipton: Yes. And actually, as a result of a lawsuit that we did a number of years ago, having to do with abuse of children with disabilities by school staff—we did a number of cases like that in the early nineties—as a result of one of those cases, we had the opportunity as part of the settlement to work with the Department of Education on developing behavior intervention regulations. California has probably the most progressive behavior intervention regulations of any place in the country because of that.

DREDF influences anti-aversive behavior regulations

Jacobson: Could you define behavior intervention regulations?

Lipton: Yes. Well, California passed a law as a result of a couple of deaths in—I think it was either group homes, or residential school settings—of kids being restrained. I think one child was wrapped in a blanket and suffocated to death, due to the way that they were restraining him because of behavior problems. There were, I believe, a couple of incidents like this in the eighties. There was this effort to pass a law in California that would prevent the schools, and residential facilities, and other settings from using what are called "aversive behavioral approaches."

Aversive behavioral approaches are basically negative behavior approaches, where there is some negative consequence to the behavior, and often it has been a very serious physical negative consequence. I mean, things that have really bordered on things some of us would consider torture of kids: spraying them in the faces many times a day if they misbehaved, putting earphones on them with very loud noises, restraining them physically. In one of the cases we were involved in, the teacher was putting Tabasco on the tongues of children, these were kids with Down's syndrome, and other kids with severe cognitive disabilities. You know, to banging kids' heads on walls, to doing all kinds of things. Some of them look less negative than others, like time-outs. But there are kids who are being timed out for big portions of their school day, and really isolated from other kids, for behavior that is difficult for them to control—that is their disability, that they have difficulty controlling their behavior.

So at any rate, because of a couple of very extreme incidents in California, the legislature was trying to pass this law that prohibited the use of anything aversive. It was very controversial, because some school people, some board-and-care people, some residential places said that it really tied their hands. There were a few people in the country who were doing really negative behavior stuff, who had the ear of some legislators. Anyway, finally, the only thing the legislature was able to pass was a law that said that the schools may not do anything to students which would result in physical pain or trauma, and directed the Department of Education to come up with regulations to define what that meant. I mean, literally the law was like that, one line.

The Department of Education was very much against the use of aversives, to their credit. They really thought some of the things that were going on in schools was really terrible. We just happened to bring this lawsuit about at the time when they were going to start working on the regulations. As part of the settlement of the lawsuit, they agreed that we would have a big opportunity to provide input into these regulations. What actually happened was that the department used the experts we were relying on to help them draft the regulations. What these regulations basically do is they define, they say that schools, when a child is exhibiting certain kinds of behavior problems, the school must do a behavioral assessment. It defines what that assessment has to consist of. The assessment has to consist of a lot of careful observation of what precipitates the behavior, describing the behaviors, describing what happens after the behaviors, interviewing the parents, working with the teachers; it is a very comprehensive list of what has to go into a behavioral assessment.

The key piece of it is trying to understand what precipitates it, because in many cases, if you just eradicate what precipitates it, the behavior goes away [laughs]—and the approach is more towards manipulating the environment to minimize the opportunities for that behavior, or the need for that behavior to manifest itself. Anyway, once you have done this supposedly comprehensive assessment, the IEP team comes together to develop a plan. The plan may be, "Don't let Jimmy sit next to Peter because, you know, when he sits next to Peter, he gets into trouble." Or it could be, "Don't make Jimmy sit in the seat for more than ten minutes. Jimmy is going to need a break. He can't sit still that long. And so after ten minutes, make him the monitor who erases the black board, so he can get up and do something else." It may also consist of, depending on the cognitive abilities of the child, of giving the child reminders that, you know, something, "X is going—"

[Tape 10, Side A]

Lipton: At any rate, we were talking about these behavior intervention regulations. It described what is supposed to be in an intervention plan. It described the qualifications of the people developing, doing the assessments. It prohibited the use of aversive, negative behavioral approaches, prescribed what kinds of things you could do in emergency situations with regard to restraint, you know, a child who is really out of control, and who really may need to be, at least momentarily, physically restrained—and who is allowed to do that, and what training people should have, and under what circumstances it's okay to do that.

So the thing that was very progressive about these regulations were—it's allowing only the use of positive interventions, things that were not punitive, you know, using praise, rewards, consequences that would be desirable to the child. Some people argue, "Well, aren't you really punishing the child when you don't give them the lollipop?" And, you know, probably you are, but it's not the same thing as putting a kid in isolation. But the approach now—and the regulations incorporate this very much so—is again, trying to manipulate the environment as much as you can to avoid the behavior, and also trying to understand what purpose the behavior serves for the child—and seeing if you can help, if it is an attention-getting thing, help the child learn other, more positive ways to get attention than by exhibiting some negative behavior.

Jacobson: How long ago were these regulations implemented?

Lipton: I think it was the early nineties that they were implemented. During reauthorization of IDEA in the nineties, we used those regulations, I mean, we told the department—and members of Congress—that these are the kinds of things, the things that we have in regulations in California, were really a model for what should go on when kids start exhibiting serious behavior problems, rather than suspending them and throwing them out of school, that this behavioral approach was, you know, a much better approach. Consequently, in the amended law, when kids have engaged in some serious behavior problems, the IEP teams have to look at whether or not a behavioral assessment was done, and if not, to do one and develop a plan. So we had some impact that way. There was never any mention before in the law of behavioral assessments or positive intervention plans.

DREDF: a catalyst

Jacobson: I know that we went off on a tangent, and we were going to talk about your family and Chloe but I find this fascinating, because I don't think a lot of people out there are aware of what has gone on and how DREDF has had a significant role—.

Lipton: Yes. We're not very good at DREDF, and it has always been the case, at publicizing what we do.

Jacobson: Yes.

Lipton: And as I am telling you all of these things, I am realizing that there are many other people who worked on a lot of these things at the national level, in the state, who we worked with. But all things considered, I think that we have played, you know, a key role sort of as a catalyst in bringing other people into working on some of these issues. It's kind of interesting to me as I'm talking to hear that we have done things at the state level, the national level, and at the IEP level, like just going to those IEP meetings with Jimmy Peters. I knew what the case was about, and how all of these things sort of worked together. I think we have had really a substantial role, and we're not good at telling that story.

Jacobson: I mean, I think it is so incredible hearing about DREDF's role at the national level—

Lipton: Yes.

Jacobson: —I knew about that, but I was not really aware that you would go in at the local level and work with local districts and how that really has broadened your knowledge of the whole issue of disability in education.

Lipton: And special education.

Jacobson: Yes.

Lipton: Yes. I mean, I feel like if you're going to be an advocate at a state or national level, you've got to have been in the trenches for some period of time. For a lot, to understand the issues, to understand how the changes in the law and the regs impact kids, to also understand the dynamics that go on between parents and school districts. The IDEA was very revolutionary in that it really gave parents a role that parents have never had in special ed, regular ed, or in anything in education, in a role in decision making.

For many years it was really—and it still is—difficult for administrators, you know, and so—not that parents have the say, by any means, they don't. [laughs] That's another kind of thing, actually, that was brought to Congress, how, you know, parents dictate this and dictate that. I have *never* been to an IEP meeting where they say, "Oh parent, what do you want?" Parent says, "This is what I want." "Oh, okay." You know—if it doesn't agree with what the school district wants to do, there is no way that they just write that as the IEP, what the parent says. Never have I been at an IEP meeting where that happens, unless the school is really okay with it.

So this notion that parents are calling the shots is so far off. But parents do have ways, through hearings, to really challenge school decisions and to make sure—at least they have opportunities for input. In a way, my daughter, who was not in special ed—I never had anything to say about her education. She went to a private school for many years. You'd think I'd have something to say, considering how much money we paid. And we had nothing to say, it was like, "You don't like it, leave."

Jacobson: You're talking about Daria?

Lipton: Yes, about Daria. And then when she went to public high school, I mean, you know, we were even more out of the picture. Nobody asked our opinion about anything, or cared. Whereas with Chloe, there were meetings to find out what I—at least where I had opportunities to say what I thought she needed. So it's very progressive, the law. We've gotten involved in a variety of issues at DREDF at a lot of different levels. Considering the smallness of our staff and our resources, I think we've been pretty effective.

— 87 —

VI. Remarriage, Birth of Second Child, Chloe's Transition to Adulthood

Impact of having a child with a disability on the dating scene; meeting Jim

Jacobson: Let's get back to your family. How old was Chloe when Daria was born?

Lipton: Eleven. She was eleven. I was separated from Chloe's father from the time she was four, and then met Jim, and was kind of, was really basically a single parent from the time Chloe was four until about nine, eight or nine, when I met Jim. Chloe's father was very involved, and helped take care of her a lot in those years. I was working, and I was going out with other—you know, with different men, and their reactions to Chloe were interesting [laughs].

Jacobson: Tell me about some of them.

Lipton: I guess, the overall feeling that I had was that—and I never could figure this out, if this was really—how much—I know some of it is true—how much of it was my own thing, but I always had the feeling that there was a point at which men were reluctant to get too involved with me, because of Chloe. Now, that's a good excuse! [laughs] I mean, that's why I say I don't know. I'm sure that that played a big part in some of the relationships I had. It was difficult for me to handle, and it made me very wary of getting involved with people. You know, we just came as a pair, that was it [laughs], like it or leave it. But it was hard, it was very difficult.

Those years, those were in the, I guess, late seventies, early eighties—the disability movement has evolved a lot since then, and in a short period of time. You know, I felt so much of the stigma and isolation of having a child with the kinds of disabilities Chloe has.

Jacobson: Even in the Bay Area?

Lipton: Even in the Bay Area, even in the Bay Area, I definitely felt it. Some parents I know had much worse experiences, friends who stopped seeing them, relatives, I think we talked about this early on, relatives who even couldn't relate to it, and kind of withdrew.

— 88 —

I never had that, and certainly not from any good friends or family. But it just felt so stigmatizing and isolating. When I was dating, you know, there was always, like, do I tell them now, the first five minutes? Do I not have to say anything until two dates from now? It was just always there as a big issue.

Anyway, when I met Jim—and I did, I had one man I was seeing for about a year and a half, who—actually, they all were—the ones I spent any amount of time with were very, very nice to Chloe. And Chloe would get—she gets very attached to people, and likes people. For her those were positive experiences. But I always felt certain limitations.

When I met Jim, that limitation didn't seem to be there. In fact, he seemed to somewhat thrive on feeling that he had something to give her, and something to give me, with respect to her. I don't know why [laughs]. I mean, he has a disability himself. He has a very significant visual disability, so maybe—but he had his own struggles about his disability, and suffered tremendously because of it and the way he was treated as a child by other kids, and teachers. But he wasn't afraid of it, or afraid of getting involved with me because of it. A couple of years later he may have regretted it [laughter] when we were going through some really rough times with Chloe and my ex-husband, and all that, but he seemed to have no hesitation at the beginning, and that was kind of stunning to me to see.

Birth of Daria

Jacobson: How did you decide to have another child?

Lipton: Well, I think I pretty much knew all along that I would like to have another child, given the right circumstances. And Jim also wanted to have a child, so—it was scary to me, because my previous experiences with pregnancies have been so traumatic. But I felt open to trying it again. The pediatrician I was seeing encouraged it, because he felt that the two problems I had had before were, for one thing, were unrelated to each other, and the likelihood of either of those things happening again were pretty—I mean, he thought remote. So we just did it, and decided we would give it a try. After Daria was born I thought, well, maybe we should have one more. Then I just thought no, I can't, I just couldn't go through the anxiety of another pregnancy. Although the pregnancy with her was quite easy.

Assistance with Chloe; some sibling rivalry

Jacobson: What was it like in terms of day-to-day, because you had Chloe, who was very dependent on you, and then you had a baby, and that is a lot of responsibility?

Lipton: Well, I think, because Chloe was eleven when Daria was born, we had for some time before she was—within a couple of years before Daria was born—started to have more and more help with Chloe at home. Actually, I had all the time, since she was four or five, when I went back to school and work, so—.

Jacobson: What kind of help?

Lipton: Well, it was basically like babysitting or child care help that was paid for largely by the regional center—

Jacobson: Okay.

Lipton: —and some of it I paid for. So she was used to having other people, even if I was home, other people helping with her and being with her, because her needs were so great, not just physically, but to do things with her, because there were so many things she couldn't do by herself, or she couldn't get engaged in on her own. So it turned out that when Daria was born, she was very used to—she had a few, a couple of really good relationships with people who were helping with her. Also, she was gone at school all day, and went to an after-school program. On the weekends she spent a lot of time with her father, at those years. So in some ways it wasn't that different from having a child without disabilities eleven or twelve years old, and a baby in the house. And I would make time everyday or pretty often for me to spend time just with Chloe. So I thought Chloe handled it very well, and our family kind of worked it out.

The other thing is with Chloe, there are some things she enjoys doing with Jim very much. Like Jim is a huge jazz collector, and literally listens to music several hours a day. Well, I have never gotten nearly that involved in the music. Chloe adores it. [Exchanges "Hi"s with someone who walked in the room] One of the things that really helped was that Chloe loves music. She would go down, Jim has a room downstairs in the house with his literally thousands of records and CDs. She loves being down there with him, and he plays all different kinds of music for her.

So he spent a lot of time with her, I spent some time with her, she had attendants or other people with her. You know, there was some sibling stuff, I mean [laughs] Daria will kill me for saying this, but [laughs] there was some definite sibling rivalry between them, and different things they would each do to get our attention. Daria told me a couple of years ago that sometimes she used to whisper in Chloe's ear. See, she always thought Chloe got too much attention, and she would whisper in Chloe's ear, "Mommy loves me more than she loves you."

Then Chloe would get furious, and she would pinch her, or grab her arm and bite her, or pinch her, or try to run her over with the wheelchair. Then we wouldn't have known what happened, and we would just see that Daria would say, "Mom, Chloe tried to—or Chloe bit me," or, "Chloe did this to me." Then we would say, "Chloe, you can't do that." You know, we wouldn't know what had actually preceded this incident, and we would get all mad at Chloe. And it was years later that Daria—at some point I think we caught on, that Daria was doing something to provoke Chloe—

Jacobson: [laughs]

Lipton: —but it was years later that she told us. So they had some of the kind of usual stuff between them, but also very tender feelings for each other. So, you know, it has been, I guess the way it is between all siblings, or most siblings, basically.

Jacobson: Chloe is eleven years older than Daria—.

Lipton: Yes.

Transition program at Contra Costa Community College

Jacobson: Let's go back to talking about Chloe's transition from high school. Tell me a little bit about that.

Lipton: You mean the transition from high school to the program she was in until she was twenty-two, or you mean after that?

Jacobson: Well, you said that you really didn't like the transition program.

Lipton: Yes.

Jacobson: Did she go for awhile? Where did she go after high school?

Lipton: Well, after high school she went into the transition program run by the school district for special ed kids who were staying in school until twenty-two, which as I said earlier, was mainly the kids with cognitive disabilities, some with just physical disabilities, but mainly it was kids with cognitive disabilities. The program was run by the district, but located at Contra Costa Community College. While Chloe was there I was always pushing for her to go to regular classes on the campus. I mean, they were right there. And also to do some, have some work experience as part of her program. It was just a huge struggle, because they would always put the special ed kids in the same three classes. One of them was ceramics. And for a semester she went to this ceramics class three hours a day, where she just sat there, just like banging [Lipton makes banging noise] on pieces of clay that she could barely reach. She couldn't manipulate anything with her hands; it was a complete, total waste of time. About a month into this, because of my work, and knowing a lot of the people at San Francisco State University in special ed, I kind of asked a couple of them for a favor, to go and observe Chloe's program and write up some report—I thought I needed that kind of expert support—not only to criticize what they were doing, but to give us ideas about what she could be doing that would be more productive. Anyway, it turned out about four or five of them decided to do it together, this evaluation, which was more than I expected. They each spent a day following Chloe around, and then they wrote this report [laughs], in which they politely tried to say this was the biggest waste of time they had seen in a long time, and said all of the time that was wasted, the inappropriate classes, the—and then they gave a whole bunch of recommendations. So we were able to get some of the recommendations implemented, but after a year or two I decided that I really needed to put my energy into developing what was going to come next.

Jacobson: Okay, before we go to that, tell me what a transition program was supposed to do.

Lipton: Supposed to prepare the student for what they were going to be doing when they leave school. So for example, it was supposed to be focusing on developing independent living skills, work skills, an ability to be involved in educational, recreational activities, social activities, using transportation, kind of to give them an opportunity to try out different kinds of activities that would be available, like classes at community colleges, or city recreation programs, to try these things out—

[Tape 10, Side B]

Lipton: And she was in this program for, I guess, about three, almost four years. There were times when it was better than other times. But basically it was not—they could have really done a lot more in that program with Chloe and the other kids, as far as I was concerned. The teachers had been there doing this for a number of years, and it seemed were just doing things the easiest way, things that would require the least amount of effort on their part, for the most part. So after awhile I realized I was sort of spinning my wheels, and could make a little bit of change, but nothing that substantial. Then we started to panic, I mean literally panic about what was going to be next.

Also, I think the lack of—one of the reasons that the transition program wasn't that great, was nobody really had a vision of what anybody was going to do, certainly not Chloe. When they left school, I think some kids they saw as headed for the group home/ sheltered workshop route. And that wasn't going to be Chloe, for a number of reasons, because, first of all the sheltered workshops wouldn't take her because of her physical disabilities, because they don't provide attendant assistance, and the kinds of physical jobs they do there would not be appropriate for her. And I didn't want Chloe particularly living in a group home, and most of the decent group homes wouldn't take her anyway, because again, because she had physical disabilities. So she wasn't going to follow that path, and that was the only path they knew.

Frustrated exploration of options

Jacobson: Okay. So what did you do?

Lipton: Well, I started to meet a group of parents, mainly friends of mine, who had kids the same age. We started to meet and talk about what's next. We had two issues. One was for housing and living arrangements, and the other was like, for a day program, or work, or what are they going to do with their lives once they are living some place. It was a group of about five or six parents, and—it got pretty depressing, because we kind of didn't know—I mean, it seems, our idea of what we wanted for our kids was pretty similar, but we just didn't know where to begin. It seemed like what we wanted didn't exist, and it was just overwhelming. And then that group kind of fell apart. Two of the children passed away, and I don't know, it just kind of—it didn't keep going. Then a sort of meeting with the Regional Center, which is the agency that is really supposed to take over providing the services once kids leave school, kids who meet their eligibility criteria, mainly kids who have cognitive disabilities, developmental disabilities that are

cognitive. Anyway—and they had nothing to offer. Again, the group homes that had any kind of a decent reputation wouldn't take her, and kids like Chloe were going into these facilities that were kind of like nursing homes. And that was out of the question, as far as I was concerned.

Jacobson: Were you familiar with the CP [Cerebral Palsy] Center?

Lipton: In Oakland?

Jacobson: Yes.

Lipton: Yes. Well, not—I knew of it, and I had been there once or twice. As far as a day program goes, it didn't seem appropriate for Chloe, and it also seemed very isolated. I don't even know if they would have even taken Chloe, because of her cognitive disabilities. I'm not sure. But it seemed very isolated. Oh, there were also, in addition to sheltered workshops, there were also these like—what were called, I don't know if they are still called this, day activity centers, for kids, for adults I should say, with more severe cognitive disabilities. There is one up in Richmond at Hilltop, at the same place where she went when she was a baby. There was no way I was going to send her there. To me it just looked like a place where they were babysat—in like some huge room with fifty, sixty—I don't know. They would go out a little bit, but it was not appropriate for her, or anybody, in my opinion. But that's another story.

So there were no options. That was it. It was a day activity program—actually, the only option for her, really, was that day activity program. The only living situations—Regional Center couldn't even tell us any places to go to in our area. They sent us—I mean, literally had no place other than nursing homes, in our area, to go to. We would have had to look at group homes, you know, much further away.

Disability and delayed adolescence

Lipton: At the same time, Chloe's behavior was getting more and more difficult for us to deal with at home. I think that she had come to a point where she needed some change, where we needed some change. It was getting really difficult for us at home with her. We were able to get some more hours of help through the Regional Center, but I didn't have the energy to do the things she wanted to do. She wanted to be out doing things all the time, and, you know, a lot of it in retrospect I see as kind of adolescent oppositional stuff. But nobody ever told us that she would go through some of those developmental stages. It's sort of like everything was due to her disability. And I think her disability limited the way she could cope with certain things, but I think some of her drives for independence, for separation from us were actually, you know, very normal, developmental things. No one every talked to parents who had teenagers or kids approaching their early twenties about these issues. It's like all that other teenage stuff didn't exist for us, which I think is really—I think that's really a problem, and something we try to address in parent trainings that we do. That your kids may—whatever their disability is—they're also teenagers going through hormonal stuff, and emotional stuff, and they may do it a little differently, they may not be able to take the

car and run off, so they are going to throw a tantrum instead. But they'll find—you know, at any rate these—.

Jacobson: I think that for kids who grow up with a disability, and I think there has been some literature published about it—but I know that for myself, and for my peers and others who grew up with a disability, that a lot of what we experienced in our early twenties, or mid-twenties, or even late twenties, was really a delayed adolescence, because we were dependent on our parents.

Lipton: Right, yes.

Jacobson: So how could we rebel, and find autonomy, when we needed help going to the bathroom or getting some place?

Lipton: Were you aware of feeling rebellious then, or was it just repressed because of the reality of the situation?

Jacobson: I think it was repressed. I used to hear my nondisabled peers talk about hating their parents and they couldn't wait to get out and they were always arguing. And that was so foreign to me, and what that looks like to the outside world is it looks like maturity. But it's really not. It's repression.

Lipton: Yes, that makes a lot of sense. It really does. I mean, it would be hard to allow yourself to feel, to hate somebody you needed to help you.

Jacobson: Yes. [laughs]

Lipton: You know, for your most basic needs, and to allow yourself to feel those feelings. It could be pretty intolerable.

Jacobson: So what you were talking about with Chloe and her behavior makes a lot of sense to me.

Lipton: Yes. Yes, because I think in her late teens and her early twenties, her behavior got worse—and was more difficult. I think it was because she was trying to, you know, push away from us, but couldn't really.

Jacobson: Yes.

Lipton: And maybe even having those feelings was scary to her, and so all of it came out in these, you know, tantrums over this or that, and—.

Jacobson: And also looking at other people her age and seeing that they are getting jobs, and that they're getting married, or getting into relationships.

Lipton: Right. Yes. I think to some extent she was aware that that's what other people her age were kind of doing. So to me it meant that we really—and also her father stopped spending as much time with her, and so more of the responsibility was on us. I was working, and Daria was young and needed a lot of attention like a young kid does. It just felt like a change was just critical or we'd all shoot each other. [laughter] But there was nothing, there was—and it was one of the most depressing periods of my life, because it dawned on me that if anything was going to happen, remotely in a way that I thought would be good for her, I was going to have to make it happen. It was like the struggle, it never ends.

Forges new ground with supported living

Jacobson: Yes.

Lipton: Chloe always was in the first generation of kids. She is the first generation of kids to go through school with IDEA in effect. So it was like forging new ground, new territory all the time, as she went from elementary school, to junior high, to senior high, everything was always having to start something new. Here again we were going to have to start something new. But this time, I mean, the challenge of that just seemed so overwhelming. But we kind of plunged in, and we spent a couple of years working with a couple of consultants. The Regional Center paid—what we wanted was a supported living situation for her, which was she could live in her own house, her own apartment, with or without a roommate, disabled, nondisabled, but with twenty-four hour assistance. And to have her own home, not a group home that could kick her out if they didn't like the way she acted. You know, she didn't have to eat when someone else said it was time to eat, and she could really live as normal a life as everybody else. But there was nothing like it.

It was just at that time that people started to talk, at least in California, about this idea of supported living. The Regional Center agreed to contract with two consultants to help us figure out how to do it. Because they figured, if we could figure it out for Chloe, then it would be kind of a model for many of their other clients. The woman who was head of the Regional Center at that time was relatively progressive, and also knew that I was a lawyer at DREDF, and I was going to go to hearing, or do whatever I had to do. So—.

Jacobson: What year was this?

Lipton: Well, let's see, Chloe—this is about when she was twenty-one or so that we really—twenty maybe, when we started working on all of this in a more focused way. So that was nine years ago.

Jacobson: Ninety-three?

Lipton: Maybe a little earlier than that, '92? '91, '92, in there. So we spent two years working with these two consultants who were great, and they totally understood what it was we wanted to do. They looked at how it was being done in very few places in the country. But how to figure out the funding of it, for one thing, was really enormous, because there weren't the mechanisms. It wasn't that the money wasn't there, there weren't the mechanisms for it, to pay for the services, the attendants, twenty-four hour kind of attendants. There was no agency to actually put it together and run it, so it was like, "Wait a minute. Am I creating something that I am going to have to run for the rest of my life? What happens when I am not here able to do it?"

So there was no infrastructure, I guess, is the way to put it, to provide this sort of living option in California, or, in almost no place else in the country. Around that time though, there were some Medicaid waiver sort of options available to develop some of this kind of living situation, and Chloe was like the first one on the list. What that did was basically create a funding stream and mechanism. The Regional Center had to create—help create—little agencies that would actually put these sort of living situations together. So for two years we planned, and we had a million meetings, and they wrote up Chloe's story that is in a book they put together, and, you know, these two consultants. But we just couldn't figure out how to do it.

Jacobson: Who were they?

Lipton: Bill Allen and John Shea. They were totally on our wavelength, sort of philosophically, and how to pull it all off was another story. We had all those scenarios, we created this circle of support where you are supposed to bring people together who know the person, in this case, who know Chloe, who want to be involved in one way or another. We had all kinds of meetings. We were thinking it might be affordable if she had a roommate also with benefits. We sent flyers to all these Regional Center case managers seeing if they had other clients. The only people who were ever referred to us were parents of kids, young adults, with pretty serious behavior problems, because those were the people who kept getting kicked out of group homes. It didn't look like they were necessarily, just because they had disabilities, the right people for Chloe to live with. At any rate, we had some two or three years of, kind of it felt like spinning our wheels and not getting very far, when this Medicaid option, it was called Community—what was it, CSLA, Community Supported Living Arrangement option funded through Medicaid money in a limited way was going to be tried in California. And it is—one of the first things that had to happen, was a couple of agencies came into existence, or agencies in existence said that they would like to do this with a number of people. Chloe was really first on their list, the Regional Center list, to do this with.

Jacobson: Was this the Regional Center of Alameda County?

Lipton: Yes, it covered Alameda, Contra Costa Counties, the East Bay Regional Center [Regional Center of the East Bay].

Let me just say, just to go back for a minute, the year or so before Chloe left school and the transition program, I remember our last meetings that year feeling like we were about to be dumped into this black hole, because I had no idea—for example, Chloe's wheelchairs, we always got them through California Children Services, which was a health agency that worked with the schools. They were the ones who dealt with ordering and getting Chloe's equipment. They were no longer going to be in the picture, because—once Chloe left school. I didn't even know, well, where do I go when Chloe needs her next wheelchair? What do we do if Chloe needs physical therapy? Who is going to help us with the living thing? What day programs? What—? It was like, after going through many years of school where you knew ultimately the school district had to find and bring the services together, there was going to be nothing. Really nothing. In fact, the school kept Chloe for an extra few months while we were trying to get some things together, really as a favor to me [laughs] and to shut me up. But it was really very, very frightening, and it is one of the reasons that DREDF, we do a lot of transition trainings for parents. It is such a traumatic time.

Jacobson: Who were your resources at that time?

Lipton: Well, the only resource really was the Regional Center, and they would kind of come to the last IEP meetings, you know, when all of this planning is supposed to go on in these transition years.

Jacobson: I'm thinking about, here you were, you were working in some way with the disability movement, you knew people like Mary Lou and Judy. Would they tell you anything, or was this something they didn't know about?

Lipton: They didn't know, because—I did talk to them quite a bit about it, because they—I mean, the way they put their lives together, both of them, you know, had worked for many years.

Jacobson: Yes.

Lipton: Mary Lou struggled without attendants, any attendant assistants, until pretty recently. They didn't have the kind of disabilities that would have made them eligible for Regional Center kind of services. So what they did provide was just support, that the idea of what I wanted to do was right, that there is no reason Chloe couldn't live in an apartment, live on her own, if she had enough help. That idea was supported and reinforced. How to go about putting that together for her, they didn't have a clue about, like the rest of us.

Jacobson: [laughs]

Lipton: Judy, of course, gave me fifty-five people to call all over the country, and I did talk to some of those people, but they were in other states, and they had been dealing with different—you know, each one gave me some ideas, but I really was pretty much on my own. Some of the other parents were kind of waiting to see how things went with Chloe. A couple of the other parents had decided to put their kids in group homes for one reason or another, just the thought of starting something was too overwhelming to some parents. Other parents were a little scared about it, and were—. So I really felt out there by myself, although—and Julie Weissman was—who knew Chloe very well at that point—was very supportive, and now she is like, really, a second mother to Chloe.

Jacobson: How did Julie Weissman get involved?

Lipton: You know, we talked about that a few months ago, and I kind of can't really remember. Julie was—I think she got interested in the music therapy stuff, and started to work at this after school recreation program in Richmond developing this music therapy program—and Chloe was going there, and I think that's how I first met Julie. She—I really have to talk to her about it, because I wish I could remember better. But she and Chloe really hit it off. By the time we were going—and I also knew that Julie knew Judy, and you know, they were—oh, and I know, Julie was a client of DREDF's when she sued H's Lordships [a restaurant in Berkeley].

Jacobson: Right.

Lipton: So that was another way I knew Julie. But mainly she got to know Chloe I think through this after school program that she had some involvement with. By the time we started planning all of this, Julie was coming to all the meetings, you know, this is in the early nineties, and really was like one of the key support people, very key. At any rate, what finally happened was, that because of this CSLA, this new Medicaid way in which California could use Medicaid money, some agencies formed, or came out of the woodwork, to provide, to be what are called supported living agencies. They had like this little fair at the Regional Center, and the idea was—it was very much focused on client choice, and philosophically it was very progressive. And the clients had to have more than one agency to choose from—so there was this little fair which was in one room of the Regional Center. About six or seven agencies had tables. There was one agency that was interested in working with people with physical disabilities. The rest just wanted people with mental retardation, who didn't have physical—

Sets up supported living for Chloe

[Interview 6: October 10, 2001] [Tape 11, Side A]

Jacobson: I think last time we were talking about supported living, and how you were able to get that program started. But we really didn't go into detail about the structure or the finances, so why don't we begin that?

Lipton: Okay. I think I did talk about, last time, that when we started to think about supported living, it wasn't happening in this area. The Regional Center that covers our area, Alameda-Contra Costa County, the Regional Center in San Francisco, and Marin, they weren't doing supported living at the time we were trying to get it together.

I think I was also telling you that there were these two consultants who worked with us. The Regional Center paid for these two people, Bill Allen and John Shea to work with us, to see, to figure out how to put it together, because they figured if we could figure it out for Chloe, who needed twenty-four hour services, that it could be replicable for, you know, most of their clients. So we did, I think I described, we worked with them for really almost two years.

During that time we got together what they call a circle of support, people who are interested in helping in one way or another on an ongoing basis. Julie Weissman was involved with that, and who else? A couple of Chloe's attendants. Various friends of ours came to meetings at different times.

There were two constraints, though, we had. We came to the conclusion that we weren't going to be able to do it under the constraints we had. One of them was that the Regional Center wanted us to be able to do it for an amount of money that was absurd, that they would have paid for Chloe to be in a certain kind of group home where very little, few services are provided, not at the level of like, anything close to what they would pay for her to be in, I think they call it—I forget what they call them now, the initials—a nursing home type of facility, a skilled nursing facility, or something along those lines. It was much less—it was like $800 a month or something.

We were trying to do it by matching Chloe with somebody else who was disabled in the apartment, and combining resources, and having like one attendant for two people at night, that kind of thing. Anyway, it got very complicated finding a good match for her, and blah blah. So that was one big constraint, and we came to the conclusion, "Wait a minute, why have they limited us to this amount of money?" There was nothing legally, no reason legally they had to do that, and it was totally unrealistic.

The other constraint was that there were no agencies set up to actually put it together, manage it on a day to day basis. So we were having to do all the work of putting it together, and then we were going to have to do all the work of maintaining it day-to-day, and managing it, which sort of undercut some of the purpose of it.

Jacobson: When you say we—?

Lipton: Meaning me, our family.

Jacobson: Okay.

Lipton: So one of the purposes of doing this in the first place was so that we could get out of having to be involved in Chloe's life day-to-day, we are not going to live forever. [laughs] And we wanted to set something up that was not dependent on us, her family. So that, you know, that wasn't happening.

I realized it was going to be more work, in certain ways, having her live away, than it was even having her live at home, if I had to do all the hiring, all the paperwork, all the money stuff for the Regional Center, everything basically. So after about two years, it was looking pretty grim. We had been meeting and trying to figure it all out, when, at that time, California had started a limited program using Medicaid money to fund supported living for a small number of people, kind of a pilot project.

At any rate, Chloe was one of the first people that the Regional Center here tried to do this supported living with. In order to do that, they had to have agencies willing to manage and handle, set up a supported living program. So a number of existing agencies came forward and said—who were doing other kinds, providing other kinds of services, independent living services for people with developmental disabilities—came forward and said they would like to start it. Then there was a new agency, brand new, called East Bay Innovations, which was started by Tom Heinz and Phyllis Johnston, who unfortunately passed away about a year later. And clients such as Chloe were supposed to have choice in which agency they wanted to work with.

Jacobson: What were the other agencies?

Lipton: ARC in Alameda County, was one, hmm, I'm trying to think. There were some other agencies besides ARC, I think Las Trampas, which actually runs programs for people with behavioral disorders—I'm trying to think of—anyway, those kinds of agencies or organizations. Then there were a couple of other new ones, too, I think, besides East Bay Innovations. So there was this little fair—I think I may have explained this, but anyway—.

Jacobson: Yes.

Lipton: The only one that would take people with physical disabilities was East Bay Innovations, which—I thought Regional Center shouldn't even be contracting with people, agencies that were not—wouldn't take—.

Jacobson: Right.

Lipton: That were eliminating—I thought it was discriminatory, and they shouldn't be contracting with agencies that wouldn't take people with physical disabilities. But that is another story.

So, at any rate, East Bay Innovations, EBI, not only were they willing to, they were really open to it. I talked to Tom and Phyllis, and philosophically we were completely on the same wavelength about what supported living was about, and what it should look like, and so forth. So that changed everything. And along with the agencies came a stream of money to actually fund this, Medicaid money. So we worked with EBI for—hmm, I'm trying to think how long, maybe three-quarters of a year, to figure out all the attendant stuff, you know, what Chloe's needs were, what her life should look like, going over any medical issues.

And then the housing was a big problem. The problem was that getting her own apartment, and the rents around here, everybody knows, are astronomical. So we had to get her—she had been on a Section 8 waiting list in Contra Costa County for a couple of years already. There was some mechanism, new mechanism, whereby people with disabilities could be moved up on that list in Contra Costa. So we were able to move her up on the list. She got a Section 8 voucher finally. I think she was on a list maybe three years or something. It's one thing we did think of doing early on—putting her on the list.

Then we had to go through this big—oh, then we started to look for apartments for her in Contra Costa, mainly in around Richmond area, where we live. We were looking for new apartments, because they were more likely to be accessible, and we wanted a three-bedroom apartment, because at that point we were thinking of her having one live-in attendant, and then another room for other attendants to stay overnight. We were trying to figure out what would work best for her in terms of how many attendants, and how long shifts should be, which varies from person to person.

So, anyway, we couldn't find an appropriate apartment. We looked and looked. Then we did find one in Emeryville at the Emery Bay Apartments, which had just been built. Well, some of it had been built a couple of years before, but they built a whole new couple of additional buildings. They had three bedroom apartments that were pretty accessible, and it was a good location, because it was right a block from movie theaters, and food, and, you know, a book store, and a lot of things you could walk to, kind of an up and coming area. And since then, that whole area has grown even a lot more.

Anyway, but we had to go through this big rigamarole with the housing authority in Contra Costa County, basically to let us use her Contra Costa voucher in Alameda County, and they said we couldn't do that. Because I work at DREDF, we were able to call somebody very high up at HUD [Housing and Urban Development] in Washington, and get their advice about what to do about this problem. Well, it turned out there was some letter that had been written by someone very high up in HUD, recommending that

housing authorities let these vouchers be portable, in other words, so that you could use them outside of the county. We got this letter—which nobody knew about—and went back to—first of all, we argued that under 504 the county should modify their policies, and under Fair

Housing Act, and ADA, and 504, they should modify their policy to allow this portability for people with disabilities, because of the difficulty of finding accessible housing. That was one argument. The second was we actually found this letter saying that housing authorities could do this.

Jacobson: What year was this?

Lipton: This was, I would say, about seven years ago, because Chloe has been in the apartment about—it was about seven, seven and a half years ago, something like that, which would have been '93 or '94.

Jacobson: Do you remember the date of that letter?

Lipton: I have it at home. It had been a couple of years before that, I think.

Jacobson: Because I'm wondering if it came out in the Clinton administration, or [George H. W.] Bush?

Lipton: You know, I'm really not sure, I can't remember. It could have been either, because the time we saw the letter was so close to the change of administrations. I could look it up, if you're interested.

Jacobson: It would be amazing if it came out in the Bush—

Lipton: Administration.

Jacobson: Yes. [laughs]

Lipton: Okay, well, I'll check it out, I'll look, because I have all this stuff at home.

Jacobson: And maybe you could add that to the transcript.

Lipton: Of this interview?

Jacobson: Yes.

Lipton: Let me just write that down, to look for those letters. I was going to look for it for some other reason, actually, because we're doing a training for parents on transition, and we were going to give them some sample letters of how you could use these laws to actually get policies modified, and things like that. So I will—look for HUD letter about portability [Lipton is writing this down]. Okay.

Jacobson: And who wrote it?

Lipton: Which administration. Okay.

Okay, so we found this letter, which is fabulous—which again, if I hadn't worked at DREDF, and we hadn't known one of the assistant secretaries or something, you know, we never would have come across this. So we sent all this to the housing authority in Contra Costa. They agreed to let her use the voucher outside of the county. So that took care of one issue.

In the meantime, the apartment still would have been expensive for her, even—somewhat expensive, even with the Section 8 voucher. It turned out that the apartment complex, which is a very large one in Emeryville, had some deal with the City of Emeryville, and with BRIDGE, which is a housing development organization, nonprofit, to set aside a certain number of their apartments in this development for low-income people, families. That was kind of the way the city was fulfilling some of its obligations for low-income housing, so they had a deal with the developer, and so forth, and this other agency.

So the problem was, is that Chloe was not a family as defined in this agreement. So again we told them that they really needed to modify this, because the issue was, is that they were going to count—they count the income of everyone in the family, or everyone living there. And we didn't want them to count the income of attendants, because that would have put her over the eligibility, or something like that. I think that was one issue, and there were a couple of others, of what constitutes a family. But at any rate, we had to do a lot of advocacy to tell them—I say we, because Arlene at DREDF and myself were both working on this—to tell them that they should modify that policy, because the way it was written, it would automatically exclude people with severe disabilities who needed twenty-four hour attendant assistance, that it would just eliminate them from the program.

It turned out that BRIDGE, this housing development organization, I can't remember why now, but the ultimate decision was theirs. Meantime, there was only this one three bedroom apartment left, and we were really scared that they were about to rent it to somebody else. So we made these very frantic calls to people we knew. We looked at who was on the board of BRIDGE, and made these frantic calls to people we knew who might have connections to BRIDGE. We tracked down the executive director who was at a conference in Monterey for two days, and we faxed a letter to him basically saying that we thought it was illegal to not modify their policy for blah blah blah reasons.

Jacobson: What was his name?

Lipton: That I can't remember, but, again, I can look it up. But it took a lot of detective work for us, within a couple of hours, to find the guy, who it was we needed to talk to there, and find out where he was, because he wasn't in his office, he was at some, as I said, some conference, and track him down there, and tell his office, you know, they might get sued if they don't get in touch with him immediately, and blah blah blah. Anyway, he agreed right away to this modification.

So this meant that Chloe now, between her Section 8, and this additional subsidy through the City of Emeryville, her rent was going to be really low. So—I don't know if I should say on tape, what it was or—I don't know why not, it's not private, but—.

Jacobson: You could always edit it.

Lipton: Out, yes. Okay. Well, what it meant, I think, I can't remember the exact rents at that time, but instead of paying like, $1,100 a month, she was going to have to pay $250 a month for the apartment. So that was like, that made the whole thing extremely manageable, because her only income is SSI. The Regional Center paid for all the attendant services, that plus IHSS.

Jacobson: SSI is how much now?

Lipton: Right now, well, Chloe is legally blind as well as has other physical disabilities, cerebral palsy. So for her, right now it is $770 a month. I think it is a little less for most—blind people get all this extra stuff, as you may know.

Jacobson: Yes.

Lipton: Which is not fair, but that's the way it is. It's not that much different though. I think that most people in SSI get over $700, maybe $730 or something like that. Anyway, but hers is $770 right now. It was less at the time. So anyway, all of these things sort of came together, and we grabbed this apartment, because the rent was now very affordable, but Chloe didn't move in immediately, because we had to get the attendants and all that part of this together, and that took a few months. She did stay at the apartment, we started to furnish it, and she would stay at the apartment with one of her attendants one or two nights a week. It actually turned out to be a good transition for her. And a couple of the attendants who worked with her were people who had been working with her at home, at her house, so we knew really well. That kind of made it a lot easier for us, because we knew, and trusted the people, a couple of people who were going to be with her for a lot of the time.

Involvement with East Bay Innovations

Jacobson: Where did you find these attendants?

Lipton: Well, a couple of them, as I say, were people who had been helping us at home for awhile, and we found them through putting ads in papers. We never got—we weren't able to get much help from the agencies that Regional Center contracted with. So we would have to advertise and find the people, then they'd hire them. So these were people basically we had found, either through word of mouth, you know, through friends, or from advertising to people in particular. Then East Bay Innovations, they, a big part of what they do is recruiting people to do attendant work or direct services, so they started advertising for Chloe, and for a few—they started with just a few clients that they were supporting, and us.

Jacobson: Where are they located?

Lipton: In Oakland, they have an office in Oakland. The way it worked was they did the—they advertised for attendants. Each client had what was called—has a facilitator. I don't know if they call them facilitator or coordinator now. So, for example, Chloe has a coordinator, who has Chloe plus just two other people, and that is her job, to oversee their situation. The agency is constantly advertising and recruiting, because now they have twenty-four people in supported living.

Jacobson: So, how are they financed?

Lipton: This is all funded by the Regional Centers, and it is basically Medicaid money, as far as I understand—.

Jacobson: Very interesting.

Lipton: And also some state money, and Medicaid money. Mostly Medicaid money, I think—if not entirely. And the Regional Center always gives these agencies, by the way, a hard time, because they have certain ways, you know, they are always trying to cut costs and make the agencies cut costs. It's just a—I'm on the board of East Bay Innovations, so I'm aware of what goes on, the negotiations that go on all the time. It is a very bureaucratic, difficult process that goes on yearly.

But at any rate, EBI does the advertising, what they do is—and they screen people, and they check out references—when they find somebody who they think might be good, for example working with Chloe, or working with some other client, they would call me and Chloe, and they would set up times for us to interview them. So they did all of the initial, you know, kind of grunt work of finding people, doing initial interviews, references, all of that. They—because it is small, and they knew the clients so well, they really had a very good sense of who, what kind of people work well with who. For example, Chloe really needs kind of young, energetic people who like music, and like to, you know, go out and do things. Other people may like attendants who like to stay home and watch TV and, you know, aren't—people just are different. But they understood who would work best with Chloe, and they were very good at, you know, matching people. And we had the final say, even though EBI was hiring them. I mean, if we thought somebody really wasn't going to work, they wouldn't hire them.

Jacobson: Did they hire them at minimum wage?

Lipton: No. They were paying more than minimum wage. One of the things about EBI which has been really so outstanding, I think, is they were very committed to paying above minimum wage, and also finding a way to pay benefits. So, like now they pay, start people, attendants, people doing attendant work, at, I think, $11 or $11.50 an hour, about $11 an hour they start at. If they work over a certain number of hours a week they get health benefits, vacation time, sick time, dental.

Jacobson: Do you know how they recruit?

Lipton: They recruit through, largely through ads in local papers, like *The [East Bay] Express*, and there's one in Montclaire [*The Montclarion*]. They also—they've tried everything, through the colleges, you know. The ILCs [independent living centers] have never been a good resource, they've tried that. Through colleges, through—they've tried everything, nursing programs, social work programs, graduate programs, things like that. A lot of word of mouth. People who have a friend who has a friend, that often works really well.

Jacobson: Is there a high turnover?

Lipton: There is a high turnover, but less than there is in other agencies. In fact they've had some people who have been there—Chloe had one attendant they hired—well, she had one person who worked with her for about five years, another for six years who just left recently. Many of her attendants have stayed for at least a couple of years. So they have less turnover than other agencies, and that's with people who are physically disabled hiring their own attendants have. I think that is because the pay has been a little better, and the benefits. And also, I think people like working for this agency. There is a lot of camaraderie in terms of feeling like they're part of a movement for supported living, and—

[Tape 11, Side B]

Jacobson: So what else does EBI provide?

Lipton: Well, they have two other programs besides supported living. They started with supported living, and after that got going they decided they were only—they have now twenty-four people they are supporting. They feel that that is a lot, and they want to keep it personal, and feel like they really know their clients. Also, until some of the funding negotiations change, they want to keep it at that number. They run two other programs. One is Independent Living Services, and that is basically for people with developmental disabilities who are living on their own who need some support, but don't need as intensive support as the supported living people. So they may have people they go to once a week, or twice a week, to help them with shopping, with banking, with cooking, with really, whatever they need. They are able to live on their own, but they need ongoing support. So the Regional Center pays for that too. That they have more clients for, because it is not as intensive. I'm not sure of the numbers right now. And different, mostly it is different staff working that, sometimes there is some overlap with the supported living.

The third program they run, and this started maybe a year and a half ago, is supported employment. They have a very good track record of getting jobs for a lot of their clients. And the clients come through rehab, and EBI does the job development, the job coaching, and all of that stuff. They've just done incredibly well, getting people jobs. So those are the three programs. Tom is just—who runs it—you know, he handles the money perfectly, and we have never really had any financial crisis, despite the Regional Center's constant pressure and squeezing the agency, you know, wanting them to spend less on administration, which they don't spend very much on anyway—and less on services. Tom always has to explain why they have to pay what they do, blah blah blah. Anyway, they have a lot of—you know, there are problems too. There is enough turnover so that they are constantly trying to recruit. In the last few years, changing now, I guess, when unemployment was very low, it was really hard, I mean, to find people, good people. They won't just take—they're picky about who they take, they're very selective. And the clients really get to make the final decisions. Some of their clients are able to be very involved and active in making decisions. Chloe is less able to, and we kind of help; we make a lot of those decisions for her after she has spent time with people and we see how they kind of click.

— 105 —

Families can be involved at whatever level they want to be. There are some families who are totally uninvolved, and they see their son or daughter very occasionally, are not involved in any day-to-day stuff, and there are other families that are very involved. It really, it depends on just what the family, what they want, and how involved the client wants them to be, or the parents want, the family wants to be, and so forth. So there is a lot of—it is very individual.

So for Chloe, all of this kind of—these agencies coming into place, this pilot program that directed money to do this—we weren't constrained by the $800 a month or whatever it was the Regional Center wanted originally—and it just kind of fell into place at a point where we were almost about to give up. We got the apartment, and that was a big feat, because it did take using all the laws we knew, 504, ADA, the Fair Housing Act, to make these public agencies and organizations modify rules to fit people like Chloe, who had the kinds of needs she did. Had I not been working at DREDF or known all of this, I don't think that—it wouldn't have come together.

Jacobson: So now that you have done it for Chloe, are you taking a more assertive role in helping other families?

Lipton: Um, no. [Laughs] And I'll tell you—one reason is, after we pulled all of this off—first of all, the housing development where Chloe lives, they take other people from EBI now. Shortly after Chloe, another one of EBI's clients moved in needing the same accommodations. So it kind of opened that whole housing situation up for other people with disabilities. Also, Tom got very good at getting every single one of his clients on Section 8. He had negotiations with the local housing authority in Alameda, and it was a window of opportunity that he took advantage of. So he knows, and now he knows the housing authority people well. This whole portability issue, now everybody is doing it, because it became—HUD started encouraging it more and more. So a lot of it, in terms—is not really necessary to do some of what we had to go through initially. Tom also knows the laws well enough to know how to negotiate with landlords, and things of that nature.

So, it has helped other families a lot, plus things have changed enough, Tom has learned enough, so that I haven't been—and also we have tried to do some educating of the Regional Center case managers, you know, at a certain age to start getting their clients on Section 8 lists, and things like that—there has been some of that.

Choices, options, and a social scene for Chloe

Jacobson: I remember that you had talked about not being that satisfied with Chloe's day program. Why not?

Lipton: Well, I think I may have mentioned, there actually was no day program for her to go to.

Jacobson: Right.

Lipton: So we, a couple of years before she left school, went to United Cerebral Palsy in Oakland, and we started to talk to them about developing a program. Because a lot of the existing programs—there aren't a lot, but wherever they are—they don't want to take people with physical disabilities, because of the attendant issues. So we went to UCP—supposedly their constituents are people with cerebral palsy—and we said we've got to do something about it. And they were running some other programs in San Francisco. Anyway, they started—it's a long story, not worth going into, but they did start this program called Choices. It is a community integration program. They have no site; they don't go to a place everyday. They made a philosophical decision to not do that, because they wanted people integrated into the community. The idea was for each one of their clients to look at their interests, their needs, and put together a very individualized program. So, for example, some of the people might have some job—which Chloe—naturally, just now, about a year ago, she started working at Old Navy. We had to hire someone to find the job for her, because the program was not doing anything about it.

Jacobson: So she works at Old Navy?

Lipton: Right. Originally she worked there two mornings a week. At the moment she is working there just one morning a week, because Choices says that they don't have enough staff to go have one to one with her two mornings a week, which is another problem. Other times her program consists of going—the library has a literacy program—and to work on the computer and do stuff there. She goes to the Berkeley Y, swimming, and they were doing some also volunteer work at the Berkeley Y. There is a music therapy program that Julie Weissman has put together and has maintained. She does that one morning a week. And for each client it is supposed to be a variety of activities.

There are a lot of problems with that program. The pay is not very good, the training of the people is nil. It is very disorganized. They spend a lot of time wandering around and going to cafes. It is not supervised well. There are just a huge number of problems which we have tried to deal with over the last six years or so, and I have come to the conclusion it is never going to be fixed. We are now looking at another program that started recently in Oakland that looks like it will be better for Chloe. Hopefully in the next few months she may be switching.

Jacobson: What program?

Lipton: It's called Community Options, or Options, or something like that. People at San Francisco State University have been involved with helping develop this program. Julie Weissman, who is going to San Francisco State, knows the people who are involved with it, and so forth. So we are hoping that Chloe will be able to change. There comes a point where it's just—actually, I have never faced this quite before, feeling that no matter what you do, there is no way to improve, there is something so fundamentally wrong someplace along the line, that it is not going to get better. And Chloe says she is often bored, and she often has behavior problems there because she is bored, and—anyway, it's a problem. So that is what's happening with that.

I should tell you a little bit about when Chloe first moved out, what that was like, because by then this new Choices day program—was it—yes, it had just started. So she did have a day program. We found a live-in roommate, her name was Teresa, who was going to do some of the attendant work, but also had another job. She was working with people who are blind, and some other employment program. Teresa was this young woman in her twenties, and her family was from Mexico, and she had a boyfriend, and she had a brother who lived in San Francisco, and the rest of her family in San Diego. It was the most wonderful family. Teresa was very lively, and had her brother, and her boyfriend, and friends over all the time, which was wonderful for Chloe, because she loved having people around. Her parents would come up and visit, and stay at the apartment. Her mother would cook, and it would just be a constant party for Chloe, and they were wonderful to Chloe.

She also had—one of the attendants who worked with us, her name was Kivi—worked with Chloe at our house, continued to work with Chloe.

Jacobson: Kivi?

Lipton: Kivi. K-i-v-i.

Jacobson: Okay.

Lipton: Kivi is a lesbian, and took Chloe—the very first weekend Chloe—

Jacobson: [laughs]

Lipton: —moved into the apartment, they were in San Francisco until like 3:00 in the morning at these gay bars dancing. Chloe loved it because—and it was a community that really—Kivi used to go a lot to these dance places, and some of them were a little, I'm sure, from what I've heard, a little out there. Leather—.

Jacobson: Yes.

Lipton: Odd—

Jacobson: [laughs]

Lipton: —you know, kind of out-there places. And Chloe was going to these with Kivi. Then Chloe's other attendants went along too, just for the fun of that. They would go and stay out until 2:00, 3:00 in the morning dancing. It was a community that was very accepting of Chloe. They had a great time.

It took a little bit on my part to just let it happen, and not, you know, worry about it. I did trust Kivi, that she wouldn't put her in a really not-good situation. Chloe had been going to sleep at 8:00 at our house every night.

Jacobson: [laughs]

Lipton: She would want, she said, "I want to go to sleep. I want to go to sleep." So I told them when she moved, "You know, she likes to go to sleep early; she needs a lot of sleep." Well, forget that!

I was wrong. [laughs] So her life just was, between this roommate Teresa and Kivi, and then she had two or three other attendants who worked at different times, they all became very good friends. So there was this wonderful social scene for Chloe. They would go to movies together, and you know, all kinds of things. So it was extremely successful.

Since then things have been more up and down. There have periods that have been like that, and periods that have been kind of quieter. But right from the beginning she had no interest in coming home. She would come over to our house and say she was just visiting, she wasn't going to stay.

Adjustment to Chloe's independence: gains piece of mind

Jacobson: [laughs] How was that for you?

Lipton: I was glad she felt that way, I was very relieved. What was hard for me was, within the first few days she moved out, her attendants and roommate asked me if I intended to just drop by unannounced, which they didn't want me to do—or would I be calling first before I came over? That was our first kind of—I wouldn't say—it wasn't a confrontation, but a kind of a little bit of a struggle, about that. Because I felt like I wanted to be able to drop in unannounced, to see how things were, since Chloe can't very reliably always tell us what's going on, on the one hand. On the other hand, I felt like I needed to respect Teresa's privacy too—and respectful of the situation. So we worked something out, which was fine. I very quickly did not feel the need to just drop in unannounced, or if I did, you know, I could just—it was fine. I think they thought I was going to be doing this everyday, or something. [laughter] Which I wasn't. You know, I went there a lot initially when we had to, were finishing furnishing things, and fixing up the apartment. We had to make some things a little more accessible. But mostly I was relieved.

It was hard for me to give up control of everything, and that's what these issues were about with the attendants, and roommates. I had to give up some control, about nothing really that important, or that I saw as like potentially detrimental to Chloe. But, you know, I had to give up control just even about what she wore, and how she looked, and clothes, and I don't know, just things like that. Even her diet and her meals. There were a whole bunch of things that I was concerned about that, you know, I couldn't have control twenty-four hours a day anymore. We did have meetings and we still do regularly, once every few weeks with all the staff, Chloe's coordinator and myself. There's usually a bunch of issues like how to deal with who is doing the laundry, and—Chloe has a van of her own, she doesn't drive, but just for her use that we got for her. So there are always issues about the van, and who is repairing, and maintaining, and scheduling. And then other issues about Chloe, about things to enhance her social life, you know, having them get in touch with her old friends, and make plans to get together. It's a whole range of things that come up.

The wonderful thing is that I really can be as involved as I want to be, or not involved. I have a lot of piece of mind that if I were to disappear tomorrow, they would take care of

making sure she is going to her dental appointments, making the medical appointments, when the wheelchair is broken taking it in to be fixed, calling her doctor when they need the doctor to authorize things, getting the van repairs. When she was getting new seating for her wheelchair, you know, planning to get her there for every appointment, and who would do it. She goes to physical therapy every week, and—. There are a lot of things to coordinate, especially for someone, as you know, Denise, with a lot of equipment. Everything is always breaking.

Jacobson: Yes.

Lipton: [laughter] You know, there is just a ton of things that come up. Her glasses, her eyes, her this, her that, all the time. And they take care of that. That's their job.

Jacobson: It sounds like not only has it been a transition for Chloe, but really it has been one for you too.

Lipton: Yes. It was a very big transition for us, and it was wonderful for us, because for years we had been living in this very—our lives were very routinized, and we were always—you know, if we went out, it was like, well, had to be back in three hours, because Chloe's—we did have a lot of help with Chloe at home, especially in her teen years, but, you know, we had to be home by 10:00, or we had to—you know, if someone wouldn't show up.

Jacobson: Yes.

Lipton: And going away on a vacation without Chloe was a major production, thinking of who could stay with—making all the arrangements. When she moved out, it was like we were free of those day-to-day responsibilities in a way that I hadn't been for twenty-three years.

Jacobson: Were you surprised?

Lipton: About how I felt, or—?

Jacobson: Yes.

Lipton: Umm—. [pause]

Jacobson: Or about what the impact was?

Lipton: I was surprised at the ease of her adjustment, which made me feel like we definitely had done the right thing at the right time. For us, I don't think I really felt the whole impact of it for awhile, because initially we were there a lot. But at some point within the first few months I realized our lives had changed dramatically, and for the better, because it really was time for her to leave. She was having behavior problems with us that were making things difficult, a lot because she was bored, and we couldn't—I mean, we did a hell of a lot with her, and so did her attendants, but she needed younger people with more energy—

Jacobson: Right.

Lipton: —you know, who wanted to do the things with her she wanted to do. And she needed to separate. It was a very delayed separation, which is true with people with the kind of disabilities Chloe has—the degree of disability—it comes later.

Jacobson: Yes.

Lipton: My younger daughter, she's eighteen, and just left for college. That has been a hard separation for me. But she was separating long before that, you know, her whole teen years. The last couple of years she lived at home, she was pretty much—especially because she drove, and since she is seventeen, she was kind of off on her own. And that didn't happen with Chloe until she, you know, for another—not in any way, not even in a minimal way. So I think it was a tremendous relief for us. It wasn't hard for me. I think I was just—we had sort of come to the end of our rope in being able to cope with the whole situation, give Chloe what we thought she needed. We were both working full time, we had another, younger kid. It was really—our lives were—we were tired. So I wasn't surprised that—I guess what did surprise me was just the little things, like coming home from work and not having the house—

Jacobson: Yes. [laughs]

Lipton: —you know, Chloe and an attendant, and like people instantly on you. You know, you could actually sit down and read the newspaper before you had to talk to anybody. [laughs]

Jacobson: Yes.

Lipton: Things like that—these little small things I hadn't really thought about.

VII. Recent Years, 1994-2001

Continued work with DREDF, lawsuit against East Palo Alto, and additional cases

[Tape 12, Side A]

Jacobson: Why don't you just bring me up to date with what has been going on with you in the last seven years?

Lipton: The last seven years? [laughs]

Jacobson: Since Chloe moved out.

Lipton: Well, let's see. Work-wise I have been continuing my work at DREDF. For the last six years I have been very involved in a case which started about six years ago, yes. We sued this school district in East Palo Alto and the State Department of Education for having essentially no special education program. East Palo Alto is a small, all minority district next door to—poor—very affluent Palo Alto. That case has taken a big chunk of my time over the last six years. It has been discouraging, because despite bringing in some really good people, and experts, and consultants, the district has been extremely resistant and very little has changed for the kids. We have a great judge who is giving them six more months to get it together, and then he is probably going to order a state takeover of the district. It has gotten a lot of publicity because East Palo Alto is a very high-visible community, because it is kind of a unique community, and in terms of its history, and how it became a separate city, and run by people from the community who really started with this idea of self determination for their community. It has sort of been interesting to see how it has evolved. So that is one case I have been very involved in and committed to.

At work there were other, smaller cases I have been involved in, other cases over the last seven years, inclusion cases, cases involving abuse of disabled kids in schools. Then I have been very involved with—Congress was reauthorizing the IDEA, the federal special ed law, and I think I talked about that. I was very involved with providing input to the US Department of Ed, and Congress, and all of that. So that is another big chunk of what I have been doing, is that national policy work, and state

policy work. I have focused a lot on monitoring, which is why we sued the State Department in the East Palo Alto case, because they have an obligation to monitor the districts, to make sure they are all in compliance, and they've done a terrible job of it. So one big purpose of the case was to reform that whole states—whole monitoring system, which—there have been some significant changes made. It's not what we would like it to be, but it has changed, for the better. So I've been involved in that.

Diagnosed with lung cancer

Lipton: We, DREDF has a grant to be one of the federally funded parent training and information centers, so I supervise the parent advocates who work on that project. I talk to parents. I've been on various statewide committees and task forces, and things of that nature. So that is kind of what I have been doing.

About a year and a half ago I was diagnosed with a very rare kind of lung cancer, just out of the blue, what seemed like out of the blue—which is not curable, and the treatment—and it is not—it is hard to treat it, because of some of the unique characteristics of this particular kind of cancer. And it is pretty rare. So that was and is a huge crisis in our lives, in my life and our family's life which is ongoing. So for the last almost year and a half I have been having chemotherapy almost continuously, and work a lot, mainly at home. That part has actually been nice. But it has been just a huge crisis for me personally, spiritually, in every which way, and for our family.

So, I try to continue to do my work, and just continue day to day life as much as possible. But I don't have the energy that I had, and I have, you know, breathing, and coughing, and various symptoms that really—they're not painful, but, you know, they're there.

Jacobson: I see that you're using oxygen.

Lipton: Yes. I've been using oxygen twenty-four hours a day, since last March. That has been interesting, because it makes my disability, or medical whatever, illness, very visible, and it has been interesting seeing people's reactions to that. It was pretty, relatively easy for me to get used to carting around this oxygen tank wherever I go, having been so in the disability movement [laughter], I, you know, it was—. And also a very close friend of mine, Pam Steneberg uses oxygen, has been using oxygen, the same stuff, for years, that I am using. So it wasn't that big of an adjustment for me. Although it is interesting, because other people think, who aren't disabled, who are not so involved, you know, what a big deal it is. In fact, I had a friend of mine, a few months ago said something odd to me, a person who worked with disabled people, not disabled herself, who I consider a very sensitive person. She said to me that she thought that it was great that I was going out with the oxygen and stuff so much, and she said it would be really hard for her. And that was the first time I actually felt sort of really self-conscious about it.

Jacobson: [laughs]

— 113 —

Lipton: It made me think, well, some people like her really do see this as a big deal. But it's hard. I mean, despite having a daughter who has been stared at, looked at, blah blah blah, you know, having people look at you, and—. I don't find people staring, certainly not around here at all. They just sort of look and notice, and that's the end of it. But it's weird, I mean, I don't know, it's difficult, to some degree. I wouldn't say it's a huge issue, and it certainly doesn't stop me at all from doing anything. In fact, I find most people try to be helpful, you know, pleasant, and, so—.

But having this illness brought up a whole lot of issues that I went through initially when Chloe was first diagnosed, and in her young years, once again this whole feeling of isolation, this kind of difficulty understanding or comprehending how when something extraordinary happens to you, why, and, you know, just accepting it for what it is, and there is no reason, no explanation, no nothing. It just is. But a lot of the emotional things that I went through with Chloe in her young years have reemerged to some degree with this illness. It's interesting, I noted, with this whole World Trade Center terrorist attack, and this crisis the country or the world is in right now, one of my first reactions to it, I mean, after the first few days, was, people are living with a lot of fear and uncertainty and anxiety. I feel for the first time, since I was diagnosed, like, the rest of the world is a little bit more in sync with me, because I have been living with all of that to a very extreme degree.

Jacobson: That is a very interesting analogy.

Lipton: Yes. I have been thinking about that. And people being worried about the anthrax, and small pox, and all these very real threats. But just, you know, the media kept saying, and people kept saying, you know, from September 11 on, the world is a different place for Americans. I mean, you know, things have changed in a very deep way. And that is kind of, when you're diagnosed with this kind of an illness, from that second your life is, everything is different, so—.

Jacobson: How has it been dealing with the medical profession?

Lipton: Oh, that's interesting. Well, when I was—let's see. At first, for a few months I was having this cough. They thought I had pneumonia. Then when they realized it wasn't that, they thought I had some other kind of very rare kind of pneumonia, unusual thing. I was getting all kinds of tests. I had finally—Kaiser, we belong to Kaiser. Actually, they were pretty good at making things happen quickly once we realized this could be something pretty serious. What—I was finally—I had a couple of procedures that didn't diagnose it. Then the pulmonologist wanted to do this one last thing which I was really skeptical about his doing, because I heard it wasn't good for diagnosing what he thought it was, and blah blah blah. But at any rate, I agreed to it. It was a fine-needle biopsy, where they stick a needle in your chest and they pull out, I guess some fluid or something. And sometimes it causes a leak in the lungs, which it did with me.

So my first big battle was the day that happened in the hospital. I was in tremendous pain from—they put some device or something in my chest—what the heck was it, I don't know. I can't even remember now. But it was extremely painful. This was right after the procedure they did. Like they stapled something into my—eww, it was horrible. And I told the doctor. They were going to send me home. They said I'd have to have this thing in for a couple of days, then the leak would clear itself up. And I told the

doctor, "I can't, I can't go. I'm in so much pain, I just can't go home." So we had a big fight, argument with the doctor who did the procedure. Then a friend of mine, do you know Joanna Cooper?

Jacobson: No.

Lipton: She's a neurologist in Berkeley. She happened to call the hospital then and talked to Jim, and he told her what was going on, that they wanted to send me home. She said, "Do not let them send her home like that," and I think she talked to the doctor then.

But that was my first battle. Then, when they told me the diagnosis, after that procedure, I was in the hospital. The first two oncologists—the pulmonologist who told me the diagnosis was very kind and very compassionate.

Jacobson: This is the diagnosis—

Lipton: Right, the procedure was—

Jacobson: —of the cause of—

Lipton: Right, right.

Jacobson: Did you already know about the cancer?

Lipton: No.

Jacobson: Okay.

Lipton: When they did this needle biopsy, they were thinking it was something called bronchial, oh, the short word for it was BOOP, B-O-O-P. [laughs] It is a kind of pneumonia that they treat with steroids, and it was treatable. That's what they thought I had. But I know that the doctor—and because other tests I had came back negative for cancer. But I think the pulmonologist, he wasn't quite satisfied, that he wanted to do this one more procedure. So when this happened with the doctors, I still didn't know the diagnosis, you know, when I was arguing about not going home. They admitted me to the hospital. I wanted to be admitted, because I thought that they could deal with the pain and issues better there than if I went home, which they did. They started to give me a lot of pain medication, which helped a lot. But it wasn't until two days later that I got the diagnosis while I was in the hospital. I don't think I was really thinking it was cancer, because we had not been talking—I mean, two pulmonologists thought it was really likely this other thing. So when the doctor came and told me, it just kind of blew us away. I just was like devastated.

My younger daughter Daria was at the hospital at the time. It was my husband's birthday, it was Jim's birthday. Some friends were visiting, and they all left when the doctor came in to talk to us. Then Daria came in, right after the doctor left, he stayed with us for awhile. She just was—you know, I told her what it was, and she was just also, just devastated. It makes me cry to even think about it. She made me promise that I would just tell her the truth about whatever was happening, that was her concern. You know, and I told her that there were treatments for it, and I was going to do everything I

could, and we just had to be hopeful and all of that. But those first few days were just horrible.

Mainly, my biggest concern was the kids, was Chloe and Daria, leaving them without a mother. They didn't tell us a prognosis, like you are going to live six months, or a year, or whatever. And I didn't really ask. But they started, the doctors there, and then doctors we subsequently saw, the outcome for people with lung cancer in general is very poor, the prognosis. This cancer is a little weirder, because it's a slow-growing cancer, and it's a little—it's less predictable.

It was difficult also to know how to talk to Chloe about it, to let her know that I had this illness, but also not to make her too anxious. So that, you know, I had to think about how to do that. It comes up with her periodically. Like, when I started using the oxygen, to explain that to her. And she hears people talking, and—I don't know. There's a lot of, like, a couple of the people who work with her have this impression I wasn't telling her anything, which of course wasn't true. So we've had to kind of all talk about the whole situation, what to tell Chloe, and how to tell her—but yet not wanting to make her anxious. I mean, it's just—I don't know what is going to happen today or tomorrow. But we needed to explain something to her. So we've found some way to talk about it. When I try to talk to her about it, she kind of pretends she's not—but she does—this is kind of her MO—when she doesn't want to deal with something she will just sort of change the subject. But I know she's heard what I've said. You know, for Jim, for all of us it's been very difficult.

It's really lucky that I work at DREDF, because I couldn't possibly work at any place that was more accommodating, flexible, you know, understanding, and whatever. So that has been great. I haven't had any kind of problems dealing with that. I don't know how long I'll be able to keep working, but I'm just kind of taking things a day at a time.

So now we have in our family, Chloe's disabled, Jim's disabled [laughter] I'm disabled. And I don't know what's with Daria, she thinks she may have an ulcer. [laughter] And we've got the whole spectrum of disabilities.

Jacobson: Yes.

Lipton: Not quite any mental illness yet, but— *yet* —[laughter]. So, you know, we're kind of steeped in all of this.

Impact of illness on family; advocates for good medical treatment

Jacobson: How often do you go to chemo?

Lipton: The chemo I'm on now, and have been for a few months, is once every three weeks. One thing that has been fortunate was, is, that I haven't had any of the nausea or vomiting, or the really miserable parts of chemotherapy, in any of the different chemos I've had. So the worst is it makes me tired. But it hasn't been really unpleasant, I mean, like miserable. I might consider how much of it I want if it were.

I go every three weeks. For a few months I was going to Los Angeles, because I was in a clinical trial there, which I was getting chemotherapy plus another trial drug, which helped for awhile, and then stopped helping. The disease was progressing, so I'm not in the study any more. Since then I've been getting treatment at Kaiser in San Francisco, and had a few different chemo agents, and drugs, and—.

One thing that has been pleasant, the chemotherapy nurses I found—I was going to Cedar-Sinai Hospital in L.A., which is like going to a resort, there, and—extremely competent nurses, people are very cheerful, they're not—you know, like "you poor thing" kind of—there's just none of that. I've just been very impressed.

Oh, you were asking me about the doctors. The first two oncologists I saw, when I was first diagnosed and in the hospital, I thought were so cold and weird, that I didn't want to see either of them as my ongoing oncologist. It wasn't just me—I mean, a couple of friends were around when one or two, one or both of them came—and my family, and they thought they were really weird too. Anyway, I wound up seeing this other oncologist who is extremely nice, who I like, in San Francisco.

One thing that is a bit of a struggle is wanting to do alternative kinds of things, and try experimental things. The oncologists tend to be pretty conservative. So you kind of have to really—I mean, I've sent my oncologist so many articles—

Jacobson: [laughs]

Lipton: —and, you know, just these packages from me. [laughs]

Jacobson: Yes. [laughs] You're still advocating!

Lipton: I'm still advocating. And I've seen other people doing—into sort of more cutting-edge stuff, and alternative stuff. It's funny, though, I'm not that good of an advocate for myself, which is why people are always advised, especially with cancer or some other serious illness, to have somebody go with you to advocate for you and ask questions for you.

Jacobson: You said that you didn't like the two oncologists.

Lipton: Yes.

Jacobson: So how did you find another one?

Lipton: Well, I saw—after I was diagnosed and got out of the hospital I was there for a few days. My brother came out, he is a doctor, a psychiatrist, but he lives in New York. We just started, through people he knew, we just tried to find out who are experts in this around here. So we went to see a doctor at UCSF who brought my case before the UCSF Tumor Board to see if they thought surgery might be a possibility, and stuff like that. One of those doctors, I asked him if he knew any oncologists at Kaiser that he thought were particularly good, and he recommended this one. And somebody else recommended him. So after I had two people, you know, I thought it was worth going to him, and I did. It is very easy at Kaiser, if you don't want to see one person, to go to somebody else. I had no problem with that.

I think some of my not liking them had to do with the fact that they were not bringing me good news, and so forth. Some of it was that. But they were pretty cold, very cold. One thing that also happened, and I talked to my primary care doctor about this, was, when I was diagnosed, none of them—they had no social worker come to see me, there was no concern about my emotional well being, or knowing what kind of support I had, or about resources in the community. It was nothing. I called—actually, my primary care doctor called me when she saw the results of the test, and just said she was really sorry about the diagnosis, and she had been hoping that it wasn't cancer. I told her that I was really surprised that, you know, there was no support of any sort, or anyone to address emotionally, or psychologically, what was going on for me in our family. I told her it was just like it was, you know, twenty-eight years ago when Chloe was born.

Jacobson: Oh, yes.

Lipton: So, I think in San Francisco Kaiser they do do more in terms of—I noticed there are signs all over for—they have groups that the doctors actually run, weekly groups the oncologists run.

Jacobson: Let me turn the tape over. [tape interruption followed by a brief snippet of unrelated dialogue]

Parallel movements; internet support

[Tape 12, Side B]

Jacobson: What was the response of your primary care doctor when you said that?

Lipton: She didn't say much. I mean, she kind of didn't respond. It was weird, because she didn't really respond, or say, you know, "I will check that out," you know, "There should have been, they should have had somebody come and see you and talk to you about all—blah blah blah." She didn't say anything.

Jacobson: It really strikes me that medicine has made all these technical advances and they're so behind when it comes to their supporting patients now.

Lipton: Yes. It's true. I mean, they're really—it's interesting, because, the oncologists still have a very narrow, un-holistic approach to treatment, and you know, they're not really into nutrition, or—actually, a nutritionist did call me from Kaiser, like three months later. [laughter] I was on some—I should call her one day. Maybe she has some good ideas. But—someone gave her my name at Kaiser.

But they are very narrowly focused, and there a couple of things that I've learned about and gotten a little involved with. There is this whole movement going on, and it's very similar to what's going on in disability, kind of raising people's consciousness, and medical consciousness, about disability. Well, there's a whole parallel thing going on in the cancer world. Like a place in Marin called Common Wheel. And I don't know if you're familiar with Rachel Remmen, she wrote these books, *Kitchen Table Wisdom*.

Jacobson: Yes.

Lipton: She and—there's this whole big movement of doctors, and mental health people, and advocates, and cancer survivors trying to humanize the way medical people deal with people with cancer, with other life-threatening illnesses. So I've gone to some of these—you know, hear some of these people speak, I've read books. Common Wheel—they do these—which is this retreat place in Marin—they regularly train physicians, basically, on how to be human beings with their patients, and to listen to the patients in terms of, you know, the patients knowing what is helping them, what is not helping them. And the parallels with the disability movement are very striking. You know, in this whole idea that you have to take charge, and be an advocate. Very, very similar kinds of experiences.

The other thing that's been really helpful, I'm on this e-mail list of people, which I found through some advocacy organization, lung cancer advocacy organization of people with just this particular kind of cancer. There are lists with other kinds of lung cancers. And that has been an enormous source of support and information, because there are some people on it who are like intense researchers, and some with a lot of medical background. So they are a tremendous source of information, and keep up on every possible new drug, and trials, and all of that, and share the information with everyone.

And then just emotional support, you know, if people—it's very moving—in fact, for awhile I was thinking of writing a book about it, of the Internet as being this source of support that was, you know, that is relatively recent. I was very moved, and I am very moved by the level of support that people give each other on a very regular basis, and at a very sophisticated kind of level—and even though the list includes people from all kinds of backgrounds, and levels of education, and everything. There are about 100 people on it now. It's just very impressive. You know, it's like anything else, it's just everybody sharing this same experience. Like one thing that is very traumatic with this cancer, is every time you go for a chest scan, it is a big deal, because you find out if the cancer, if things have gotten better, worse, or stable. So when people have a scan appointment coming up, there is a lot of anxiety. And there are some people who really keep track of when people are having their scans, you know, and people write when they get their results, and if they are good everybody is so happy. If they're bad, it's, you know, "keep hoping," and "things could turn around." People really try to be positive.

So anyway, those things have been interesting to get to be aware of, these movements and different sources of support. I'm not interested in getting any more involved than I am [laughs]. I mean, you know, like becoming some big—something [laughter]—in the cancer whatever. But it has just been interesting to know it's there, and to see it, and get some of the benefits.

Thoughts on colleagues at DREDF, Judy Heumann, and Berkeley's disability community

Lipton: So I think that kind of brings me up to the present. [laughs]

Jacobson: First of all, thank you for being so open about everything. Is there anything that you have been thinking about that we haven't talked about?

Lipton: The thing that just came to mind when you asked me was thinking about DREDF, because I feel like I've had such an incredible opportunity, you know, and luck, a lot of it, to work there, and to be able to be involved in a lot of the things I've done, and to work with some of the people I've worked with who are really—like Arlene, has been really a mentor, and friend. You know, I've just learned so much from her, and Mary Lou, who I think is brilliant, as is Arlene—who I have enormous respect for, and feel like I've just, over the years, learned a lot from her. There was a period of time when Mary Lou was still working in the office, when she and I used to talk a lot about, you know, disability issues, and family, and parent issues, and, you know. And I miss having those conversations with her, because I don't get together with her so much. And Pat, who is a real character.

Jacobson: Pat Wright.

Lipton: Pat Wright, she is a complete character—

Jacobson: Yes.

Lipton: —but she's—I shouldn't say but—and she's totally brilliant at what she does. You know, watching her in action is really—in Washington—is fascinating. And I have worked with some of these people now for, you know, twenty years, and I really owe a lot to them, because I was given a lot of opportunity because of them.

Jacobson: Did you see Judy Heumann—

Lipton: Oh!

Jacobson: —over the weekend?

Lipton: Yes, yes. Judy, I have to say, had an enormous influence on me, especially in the early days of, you know, making me question all this school stuff, and all this segregation. Just watching her as an advocate in those days, I learned a lot from Judy. I just, just personally, I love her, and feel very close to her. And while she was assistant secretary, it was great to be able to work with her to the extent we could. I also think she is an amazing person, and I have beyond respect for Judy. She is one of the most principled people I think I have ever known.

It was tough when she was assistant secretary. I found myself, and so did many parents and advocates, in a bind, because people loved her so much, and trusted her, on the one hand, but yet she was still the head of a bureaucracy, which was hard to change and move. It was hard to criticize her, or criticize the department while she was there, because she takes things very personally. And, you know, there were limits, to what she could accomplish, that's just the nature of the beast. But I love Judy.

I also just feel so lucky that we live around here, that there is no other community, in the world, probably, that is better to live in, as far as having a child with a disability. I thank God for that, too, that we live where we live.

Jacobson: Even with all the difficulties?

Lipton: Yes. Even with all the difficulties.

Jacobson: [laughs]

Lipton: Yes. Well, for one thing, there is a disability community here, that—you know, it's really hard here to feel like you're the only one. [laughter] And that's so important to giving you some strength, and—to fight whatever you have to fight. You know, just walking around Berkeley, you know you're one of many people dealing with a lot of the same issues. It's just a community that I am sure is hard to find in a lot of—most places. And with all of its crazy politics here—

Jacobson: [laughs]

Lipton: —groups having trouble getting along with each other [laughs], and—I think that's true in any movement. Sometimes we think it's unique to disability. It's not [laughs]. So—.

Comment on changes

Jacobson: Can you maybe comment on the changes you have seen in the last twenty-eight years?

Lipton: Oh. Well, I think the change has actually been enormous. One thing Mary Lou used to say, and I totally agree with this, that one thing that may have done more to change consciousness to the degree it's changed, about disability in the general population, is just seeing handicapped parking spots. [laughter] I mean, she once said that, and it made such an impression, because I think it's true. Just that visibility.

Jacobson: And ramps.

Lipton: And ramps. Ramps and the parking spaces. I think things have changed a lot, I mean, in a really relatively short period of time. To us twenty-eight years may seem like a long time, but in the scheme of things, it's not. And you know, there are laws that there weren't before; there is a whole different consciousness, I think, about the place of disabled people in our society. I think there is much more awareness and acceptance of people with disabilities actually being part of the community than there was twenty-eight years ago. For parents it has changed enormously.

Jacobson: I mean, would you say that it's nationwide, or—?

Lipton: I don't know what it's like nationwide, except what I see in the media. And to the extent that that's sort of a barometer, I think it has changed nationwide. The fact, just little—you know, seeing a few disabled people in commercials—it's not changed as much as it should, because people with disabilities, it's unusual to see people with disabilities actually in shows [laughs] on television. But it's changed somewhat, so that—enough so that I think it's changed across the country. Not probably like it has in some places, like in Berkeley, or New York, or in some, you know, communities, but—.

And you know, the ADA, even with all—I mean, all the publicity when it was passed, it was a lot at the time, and there has been a lot against it. But even the publicity against it has made the issues—you know, they're more visible to people.

Jacobson: Yes.

Lipton: So I do think things have changed a lot. Unfortunately, the Supreme Court is so conservative and anti-civil rights, we're seeing a very scary erosion of the laws—the ADA in particular—that shouldn't be happening. In education, I think things have changed a lot, and then they have changed not at all. It varies from community to community. There are tons of kids still unnecessarily segregated from nondisabled kids, and that is still considered acceptable in many circles. In other places there is more inclusion going on, but I find the attitudes of administrators, school administrators, kind of shockingly unprogressive. So I think things have not changed as much in the schools as they really should have. I mean, for people like you, and for Judy, things have changed dramatically. You would just be in regular classes with some, whatever support services you needed, and that would be the end of it. But for people who have more learning issues, or behavior issues, emotional issues, things have not changed nearly as they should have.

One hopeful thing is that the expectations, though—and I may have mentioned this earlier—of parents of young kids are different from my generation. We have parents calling who *expect* their kids to go to regular preschools, and regular kindergartens, and elementary school classes. Their expectations are really different. We just were glad there was some dumpy school, orthopedically handicapped school—

Jacobson: Yes. [laughs]

Lipton: —you know. And nowadays, from the calls we get, I mean, parents would not go for that at all. So that's very hopeful. And they take it for granted, which they should. I mean, a lot of the parents don't know what the struggle has been to change that over the years.

That I think is a reflection of the just general changes in the population about disability, to some extent—and the disability independent living movement—I mean, there are so many things which have influenced that. I don't know, someone may have another point of view. I could easily see someone saying, "Hey, not that much has changed." You know, employment of people with disabilities is still pretty poor. That's a huge issue. The standard of living, and the socio-economic kind of factors, and people with disabilities still living in poverty because of lack of jobs, and stuff. Those things, I don't know if they've changed—I don't think they've changed nearly enough. We have a long, long way to go.

Jacobson: Sometimes I wonder if—I think it's a two-sided coin, in that the responsibility is not clear about if it's on the employer or the person wanting a job. Or that there are circumstances that keep people unemployed, that are additional to discrimination.

Lipton: Yes.

Jacobson: That, for instance, somebody could be qualified for a job, but may not be able to work full time.

Lipton: Yes.

Jacobson: You know?

Lipton: Yes.

Jacobson: Those are, I think, different kinds of issues that are prevalent today more than they were twenty or thirty years ago.

Lipton: That it's more prevalent, that kind of an issue.

Jacobson: Yes.

Lipton: Well, I think twenty years or more ago, if—you know, just whether the person was qualified or not to do the job full time, half time, that there would be some assumptions that they just couldn't do it, on the part of the employer, and the part of the disabled person, to some extent.

Jacobson: Yes.

Lipton: Maybe, but—and I think—

Jacobson: And now it's a little more complicated.

Lipton: Well, it is, and the question of what degree those kinds of things should be accommodated—you know, are very big issues right now. Because a lot more people could be working if we kind of had a national policy that promoted that. Because I am sure there are many employers that could afford to have people working on that basis, who think they can't.

Jacobson: Yes.

Lipton: You know, there are other issues, like I know in the blind community, I've heard that some segment of the blind community feels like the ADA has made things worse in terms of employment, because employers now think that if they hire someone who is blind, they are going to have to pay for a lot of very expensive accommodations, which is not necessarily true, because really the Department of Rehab should be doing that. Unless it is an employer that can well afford it. But there is this ambiguity about the responsibility of employers. So for people who are blind, for whom the accommodations can be quite expensive, they don't really—some people don't necessarily see the ADA as being helpful, in seeming to put all of the responsibility on the employer. I don't agree with that position, but I know—. So, it is, it's all very complicated. But these are issues, conversations we're having, that we didn't have twenty years ago; or maybe some prophets, like Mary Lou, and Pat, and Arlene [laughs], and you know, others in the disability community have anticipated them down the road.

Jacobson: Well, we're coming to the end of the tape—so, is there anything else you'd like to add?

Lipton: Not that I can think of.

Jacobson: [laughs]

Lipton: [laughs] We covered all of that.

Jacobson: We covered a great deal, so thank you again.

Lipton: Well, thank you, Denise.

Jacobson: I enjoyed this. [laughter] So thank you.

Lipton: You're very welcome. It's a very worthwhile project, or all of the history would be lost, and the disability community deserves to keep its history. So it's great what you're doing, it really is.

Jacobson: Thank you.

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