

JUNE ISAACSON KAILES  
Interviewed by  
Frances Lomas Feldman  
in the Library of the School of Social Work  
on June 4, 1998

This oral history interview was conducted by Frances Lomas Feldman on June 4, 1998, in the Arlien Johnson Social Work Library. The focus was on Mrs. Kailes' experiences growing up with a severe disability that affected speech and walking. Her mother was her advocate when this became necessary, insisting that she have the same opportunities as other children. Mrs. Kailes obtained an MSW degree from the USC School of Social Work and immediately began to work, sequentially, with disabled persons in various settings: Olive View Sanitarium, Rancho Los Amigos in Los Angeles, and others. She received considerable support, sometimes financial, from Helen Phillips Levin (herself paraplegic, and an MSW from USC) in her various activities in the community aimed at improving conditions and acceptance of individuals with disabilities. Mrs. Kailes worked for several years, becoming director of the Westside Center for Independent Living, where the interviewer was a member of the board of directors. After seven years, dissatisfied with having to concentrate on administrative and fundraising tasks rather than working directly with people confronting their disabilities, Mrs. Kailes left the agency to become a private disability consultant. She consults with agencies around the country, with firms seeking ways to deal with disability needs, and with individuals. She also continues to be an activist, but at the time of this interview, was somewhat discouraged about the attitudes she encounters.

In this interview, Mrs. Kailes spoke freely about her feelings and experience; however, some of her verbal comments may be hard to pick up because of a speech impediment. She has a world-wide web page, and information about her and her activities is available on [www.jik.com](http://www.jik.com) and this material will be drawn upon to alter or append the interview when transcribed. Mrs. Kailes signed an oral history release agreement.

FELDMAN: June, I would be interested in knowing, first, how you came to be interested in social work.

KAILES: Well, I was interested in working with people, and when I was in graduate school and earlier, in college, I majored in psychology; I was interested in counseling and that kind of thing. Toward the end of my college degree, I had a lot of time, so I started to audit some graduate courses. I was always interested in disability. I audited - actually, I took some graduate courses in rehabilitation counseling. I decided that was definitely not really.....

FELDMAN: Where was that?

KAILES: On Long Island. There were some great courses: you got to go into New York City a lot and visit all kinds of human service organizations related to disability. I saw what a limited field rehab counseling was, and I decided I definitely didn't want to do that. I thought that a masters in psychology also would be too limited, because that basically was just counseling and psychological testing, and that seemed to me to be too narrow. Social work seemed the broadest degree with the greatest flexibility. I wanted to get out of the New York area, so I looked around for places I wanted to live: more precisely, places with better weather. That was one criterion. I considered Florida, coming from the East Coast, but truly felt that Florida these seemed a kind of a backwards way of looking at civil rights and tolerating human diversity and had kind of a racist quality. I didn't want to go backwards, I wanted to go forward. So I thought California might be a more progressive place. I had a friend who had graduated the year before. She was in Los Angeles. She sent me a letter, saying it seemed like a really nice place. I had applied for a graduate in at social work at NYU, USC, UCLA, and Toronto. I always liked the City of Toronto. Oh, and Illinois, too. I got a letter from the University of Illinois, saying - this was really interesting - it said, "We're considering your letter of application, but we'd need a doctor's note saying you're okay to go to graduate school." I wrote them back and said, "Any graduate school that requires a doctor's note in order for me to be accepted to that school, I don't want to attend. Thank you very much." I crossed that one off.

FELDMAN: Did you get a response?

KAILES: No. Then I got invited to an interview at NYU. This was a very memorable experience; for the NYU interview, I had to go into the City of New York. I got up early in the morning on Long Island, I went outside, and the entire environment was covered with ice. Everything was iced over. I was clinging to the wall against my car, all dressed up. I got to the

Long Island Railroad and had to park across the street, and it was sheer ice. There was no way I could get across the street. So I found a homeless person to help me across the street. I got across the street; I got into the City; I got down to Greenwich Village; and I was crossing the street the get to this interview, and a bus came along, went through a puddle of slush and just covered me from head to foot with slush. Everyone else was just standing there. I thought, "I'm going to get the hell out of here. I don't want to live like this. This isn't quality of life. This is about oppression and the weather." I went through the interview at NYU, and it was a group interview. Very interesting. They group interview students, and that's it. When I got home, I received a letter offering me a scholarship to go to NYU. Then I thought, "I want to get out of here: I don't want to stay here." I finally received a letter from USC, late, but I was accepted, sight unseen. To be frank with you, I didn't know USC from UCLA.

FELDMAN: You're a true New Yorker!

KAILES: I'd heard of UCLA. USC just seemed like - I knew what it was. But I never heard from UCLA. I had to make a decision; I said, "Good. I'll go to USC." Sight unseen, they just accepted me. I thought, "All right. It's Los Angeles."

FELDMAN: What year was this?

KAILES: 1971 - '70, '71. I just came out here sight unseen. I'd never been to California. Never. I just knew it sounded like a great place. If I didn't like it, I'd go back to Long Island. I arranged for somebody to drive my car across the country, because I decided I was first going to Europe for a while with some friends, and when I returned to New York, I'd just go on. My car had not arrived here. I don't know where it was, but somebody was driving it across the country. My roommate said she would drive me here the first day, but she got sick, and I had to take a cab to USC from West LA. The driver said, "I don't know where the School of Social Work is."

Nobody knew anything. He just dropped me off in the middle of the place. To the first person I saw, I said, "Do you know where the School of Social Work is?" She said, "No, but I'm looking for it too." We're still good friends. That was it, and I came to school here.

FELDMAN: You did the two years consecutively?

KAILES: Right.

FELDMAN: Where did you have your field placement?

KAILES: The first one was - you know, you arrive and on the first day you get your assignment. I saw on this piece of paper that it said Rancho Los Amigos. I thought, "A ranch? What would I want to go to a ranch for?" I didn't know what it was. I had never heard of it. Rancho was my placement the first year, and LA Child Guidance Center the second year.

FELDMAN: Two good placements.

KAILES: Yes. I went to work at Rancho after that.

FELDMAN: Oh, did you? I was going to ask you what your first job was.

KAILES: Yes.

FELDMAN: What were you doing there?

KAILES: I was.....

FELDMAN: Was Elsbeth Kahn there then?

KAILES: No, but she was in and out a lot. I knew her, and I worked with her for years, training medical students, but she was not the director anymore.

FELDMAN: Who was it?

KAILES: Ruth Braden.

FELDMAN: Oh, yes. I didn't know her. I just know her name.

KAILES: It was an interesting experience.

FELDMAN: What did you do there?

KAILES: I worked on neurology service as a medical social worker - for about two or three years. The director and I didn't hit it off very well. I planned to do a lot of experimental things, and I was always getting into trouble.

FELDMAN: What kind of trouble?

KAILES: I was young; I didn't have a lot of job experience. The first thing I did was to go to the director and say, "You know, I'd like to change my supervisor. I think I could learn more from that one than this one." She looked at me like, "What is wrong with you?" That didn't work. Then I got in trouble because I started to run groups on sexuality with the psychologist. Apparently, there was some kind of unwritten rule that social workers and psychologists didn't work together. That was a no-no. Something else I didn't do very well on was that I just wanted to push the limit. That wasn't a time when that was acceptable. It was a very inflexible setting. I thought, "This isn't going to work. I'm not being tolerated here very well, and I won't move on anywhere, so I'm going to go somewhere else." I went to Olive View Mental Health and worked there for two years, in the San Fernando Valley. That was an interesting experience. I had learned a lot there, too. I learned a lot at Rancho, too. I wasn't real happy at Olive View either, because my primary work was inpatient, and it was detox -- it was for alcohol and substance abuse patients. I did learn a little bit about patients, which I liked.

FELDMAN: It was no longer just a tuberculosis hospital then?

KAILES: Oh, no. I learned a lot and made good friends, but I was still restless, the setting didn't feel right, and the staff were - not the social work staff, but the staff I worked with, were kind of just putting in their time. They loved to leave at 4:00. They weren't a very creative group. It just didn't feel expansive enough for me either.

During that time, I got involved with a group that was beginning to look at disability and civil rights and beginning to offer people with disabilities alternative kinds of services that didn't seem to exist anywhere. That was the beginning of Westside Center for Independent Living (WCIL). In about '75, '76, we started to get it together.

FELDMAN: This was before we had legislation?

KAILES: Well, yes. When I was still at Rancho, I saw a lot of people being forced into nursing homes unnecessarily; they followed medical-model approaches to disability. I got involved in the idea of independent living, and we were able to get federal money by '76 to start a center.

Originally, there were ten centers in California. Federal money came to the State, and then the State distributed it for innovation and expansion. So that was the beginning of the independent living movement.

FELDMAN: Did they distribute through the Department of Rehabilitation?

KAILES: Yes. Now that was interesting. The federal government said, "You can't use this for this," to the State. Ed Robins said, "Watch me. Tough." That was freer money; that was freer funding. There were ten original centers in California. When that money was used up, the ten original centers worked to get State money into the State budget and to fund these centers when there was no longer federal money. That's how it all began in California.

By '78, I'd been on the board and doing this, and helped direct a grant. I really wanted to work in that system and not for the County and not for the Department of Mental Health. I wrote a couple of grant requests, and finally got one funded to offer a peer support program at the center. So I left the County - Olive view.

FELDMAN: What system would that be?

KAILES: The original money came from Helen, Helen Levine and from the Phillips

Foundation. When I was at Rancho - remember Arnie Beisser

FELDMAN: Very well.

KAILES: Well, Arnie Beisser (a paraplegic psychiatrist) was active in services for Rancho. He took me aside one day and said, "Look, I know what you're doing, and there's somebody you need to know. You go see this person, Helen Levine." So I did. I didn't know who she was or what to expect. I went up to her house kind of dressed like this, you know - jeans and t-shirt. The maid answered the door, and another maid showed me in, and another maid gave me a drink. I told Helen what we were doing: she was really interested. I told her some of the things we needed. I laid it out for her. She just went ahead and did it.

FELDMAN: Had she already gotten her MSW?

KAILES: No, no, this was way before that. Way before that. She told me there was some money, and if I wrote some grants, maybe something could be done. So I did. She got some of her friends involved in volunteer work I laid out for her. The next time I went to see her, she had all these people working. She had her own little thing going.

The regional funding for the program I started came from her. Years later, she said to me, I'm thinking of getting some kind of counseling degree. I'm thinking of going to the California School of Psychology (or something like that)." I said, "That's good, but social work is a more diverse degree. You might want to consider that." She said, "I never thought of that." I said, "Well, think about it. Think about it." So it was I who pulled her in the other direction. She was involved for a long time.

FELDMAN: I knew her as a student.

KAILES: She was on the board, and originally, we had to raise money just to get through the first year to get the second year money and the third year money. She was helpful in all that, too.

She was a real find.

FELDMAN: That's great!

KAILES: We would disagree, and we would fight. But we had a lot in common. It was interesting the way she would proceed. After that, I went to work at the Westside Center for Independent Living. Then I became the Director after that.

FELDMAN: You didn't start as the Director?

KAILES: No. A lot of people thought I did.

FELDMAN: I thought you did.

KAILES: No.

FELDMAN: Who was directing the agency at the time?

KAILES: There were a few people. First there was Doug Martin, then there was Neil Jacobson for a year, and then me.

FELDMAN: I didn't come on the board until you were the Executive.

KAILES: And what year was that?

FELDMAN: I don't remember.

KAILES: It would have to have been between '81 and '89.

FELDMAN: It was in the early '80s.

KAILES: I was there for about eight years, and I learned a lot. I didn't know a whole lot about management, but I learned very quickly. I did get tired of it after about seven years. I was doing a lot of management maintenance, and what I would call "management minutia." I really felt it. It was only 25 percent of the time that I was doing what I wanted to do, which was advocacy and public policy change and training and more hands-on work and more writing. I'd always done some consulting during those years on the side. I just really got tired and I thought, "I'm not

going to do this any more. I'm just tired of it. I'll just go off and see what I can do on my own." I've been doing that ever since, for nine years.

FELDMAN: Tell me what you're doing.

KAILES: Most of my work is with people I've always worked with before. It's just a natural outgrowth of things I was doing as the director of WCIL.

FELDMAN: With organizations and individuals?

KAILES: Mostly organizations. I do a lot of training. Most of my payments are sub-contracts under government grants. I do a lot of training for independent living across the country. I'm a training director on a government grant. We're into our second three years of funding under Rehab Services Administration of the Department of Education. That is about thirty percent of my time. Then I worked for a Research and Training Center on aging and disability out of Rancho. I did a lot of the dissemination of information with disability. That is about ten percent of my time right now. Then I do work with the Research and Training Center on managed care and disability. That is out of Houston, Texas and Washington, D.C. That is about fifteen percent of my time. I'm also a part-time Federal employee. I have a Presidential Clinton appointment to the Access Board that deals with disability architectural code in this country. I don't know what percentage of time that is, but it's there. Then I do some little things on the side. I do some work for the Getty Museum, work for shopping malls or work for businesses concerned with ADA. I've done work in the field of system technology and disaster preparedness for the disabled.. I've done some work for the LA Food and Shelter Program in terms of looking at their sites and working with them to make them accessible. I'm not bored. There is a lot of variety.

FELDMAN: What title do you use?

KAILES: Disability Policy Consultant.

FELDMAN: How do people know about you?

KAILES: Primarily word of mouth. Yes, word of mouth.

FELDMAN: That's your professional side. Now, will you back up and tell me about your own disability?

KAILES: Okay. I was born CP, cerebral palsy, so I've always lived with a disability. It affects my balance, and my walking, and my coordination. It's a disability that supposedly stays the same. It doesn't really get any better or any worse. However, as you get older, things do change. There are surprises that you never anticipate.

FELDMAN: For example?

KAILES: As people get older, their balance isn't as good as it used to be. If you take that and add that on to somebody who doesn't have good balance to begin with, all of a sudden, there's a major impact that's not expected or predicted. When you use your body in atypical ways, you have more aches and pains and that sort of thing. I've actually done a lot of work in that area, writing about it and saying, "Hey! You have to get on this early so you can begin to correct some of these things." You can predict what's going to happen, and there are preventative kinds of things to mitigate these problems. I've been doing a lot of work in that area. When I travel - I travel half the time outside of Los Angeles. About five years ago, I was getting these jobs in shopping malls, at the Getty, and I found I just couldn't walk around those huge places. So I started to rent a scooter. Then I decided, "This is great! Why should I waste the energy walking when I could use this." Except I got a scooter, and that makes traveling a lot easier.

FELDMAN: Do you carry it in your car, too?

KAILES: Yes. I carry the computers and the training notebooks and the suitcases and a scooter now. Probably if I was still on this campus and had to walk around a lot, I'd use it here, too.

Probably I should have used it a long time ago. It would have saved a lot of energy and time.

FELDMAN: It sounds like a marvelous expedient.

KAILES: It is. But you know, it's a value-system problem. People in our society value walking to the degree where it's not even functional. People just don't think about their options. You can walk until you drop instead. The value is in walking instead of mobility. The value should be mobility.

FELDMAN: Okay. I want to ask you to back up again to personal experiences. As you were growing up, what kinds of situations did you encounter because of your disability? How did you deal with some of them? What kind of a family picture did you have?

KAILES: I had a mother who was very assertive and wouldn't take no for an answer. She would just go out and fight for whatever I needed. I had a father who was pretty careful - "be careful! Be careful!" - the opposite of me; I'm a real risk taker. I had a younger sister. In terms of the disability while growing up, I was mainstreamed in second grade - third grade - before there was any such law. I determined that it was better not to acknowledge disability and not to answer anything special, because if you acknowledged disability, then people would treat you differently, and you wouldn't get to do what everybody else did. Therefore, it was better to not say anything and just pass. I did that for years and years until I got to college. It was ridiculous at times, but I just kept that attitude in my head, and I got it from society. The only role model I had was somebody who walked around the neighborhood selling pencils. I didn't want to sell pencils. I thought, "I'm not going to do this. I don't want anything to do with that." Instead of asking for things that would make it easier, I didn't, unless my mother intervened and said things like, "You are going to get two sets of books, so you don't have to carry one home in the snow." Or, "You are going to learn how to type early, so you can keep up with writing." That kind of thing.

FELDMAN: So she was looking for ways where you could be self-sufficient?

KAILES: Right. I'm sure she did run interference for me with the school district and that kind of thing. I do remember applying for a job in the library once and not getting it because they said I couldn't carry the books, or I couldn't climb a ladder. Well, those were the days when I was a teenager, and I was still not willing to acknowledge that I was different, and I wasn't going to fight for anything. Of course, there was no ADA where it would be a very easy accommodation to give me a stepladder with a railing or a pushcart for the books. I felt that was a real job discrimination experience, but I wasn't ready, at that point, to fight.

FELDMAN: When did you become ready?

KAILES: In college when I met a lot of other people with disabilities. We were on a campus that was supposedly "accessible," but it really wasn't. It was one of the campuses that got money from the Ford Foundation to eliminate some architectural barriers, but who they defined as accessible, and what people needed were two different things.

I met a group of other people with disabilities in the late 60's. Actually, my experience paralleled the experience of many other people across the country who for the first time met other people with disabilities on campuses and started to make some noise about what wasn't right.

The time was right.....

FELDMAN: You joined forces with others then?

KAILES: You know, we had the Viet Nam War, we had the consumer movement, we had Ralph Nadar, we had the beginning of the women's rights movement -- all those messages were about fighting for rights and civil rights. It was a natural. That was in college. Maurie Hamovitch, Dean of Social work said to me the other night, "You know, I remember you came to me one day and said, 'There's no elevator in these buildings, and these steps are awful.'"

FELDMAN: We were in the old Law Center building when you came.

KAILES: Yes. He went to the President or something, and said, "I've got this student and she's really complaining." And he was told, "Tell her to file a law suit or something." And Maurie said, "Well then what?" (She laughed a little at this) Nothing happened, though. I had forgotten about that.

FELDMAN: They did finally get an elevator in that building. You must have been gone.

KAILES: Yes. I remember working with people on this campus do to little things too. But this was a very slow go on this campus. This campus is a mess.

FELDMAN: You mean the whole campus?

KAILES: The whole campus is a mess. No access, initially.

FELDMAN: Is that still true?

KAILES: I haven't done a survey, here, but I assume things are much better. They'd have to be. You'd have to comply with the law.

FELDMAN: Yes, because we have many paraplegics, for example. I haven't heard any complaints about anyone having trouble getting around.

KAILES: Yes, you'd be in court a lot. This is a resource-rich campus. They have no excuse at all. None.

FELDMAN: Tell me some of the things that you've encountered. I guess really what I'd like to know is your view of how society's attitudes have changed about disability. What do you see in that picture?

KAILES: I think that younger people are more accepting of disability, because they've grown up with disabled students side-by-side in the classroom. It's more of a natural occurrence of the human condition. But, for the most part, attitudes don't change very quickly. It's the law that

changes people's behavior. What really convinces me of that is when you travel outside of the United States, and you observe new construction - things like the Sheraton or the Hard Rock Café or any hotel chain. They had to comply with access in this country. Yet right outside the border, for new buildings, they've done nothing. It kind of tells you that the law is what makes the real change; the attitudes just don't change that quickly. It's scary. It's very blatant. It just hits you like - you'd think they'd get it, that it increases their market, it increases conveniences, better designs. They don't get it. It's shocking! Shocking to me!

FELDMAN: Are there still pockets in the United States where there's a problem?

KAILES: All over, because the laws are only enforced by the people who need them.

FELDMAN: I'd imagine it's state by state.

KAILES: Well, the Federal Government is so backlogged by enforcement, it's a mess. A mess. Unless individuals take things into their own hands, get lawyers, do things, things don't happen very quickly. There have been changes. You can see them all over. But it's still too slow.

When you talk about attitude change, I'm not convinced. A long time ago, I stopped putting a whole lot of energy into the attitude change and just realized it would have to be in the legal laws changing. People have to obey the law. Changes in attitude could take twenty-five lifetimes.

FELDMAN: How much are you involved in pursuing change in laws, either through court action or through legislation?

KAILES: Actually through legislation or regulation. I worked on the regulations for the Telecommunications Act, Section 255, that mandates that health communication services and telecommunications equipment has to be accessible to people with a variety of hearing, vision,

among other cognitive kinds of disabilities. That's brand new, and that's far-reaching. That's the information age. That's the next century. Those are the improvements in the next century for people with disabilities. I'm working on that. I'm working a lot on strengthening the access code through the Access Board, which is a part-time Federal position. Then there's an effort to move money -- redirect funds -- away from nursing homes into better community-based services for people so they can get what they need to remain in their homes, in a non-medical model kind of service system.

FELDMAN: What kind of agencies do you see providing these services?

KAILES: You mean for community-based? Well, so far, they're real medical-model agencies. I mean they're home health agencies. They really need changing. A lot of it is so medical-based and very overpriced. If they would look at the system, a lot of the help people need to remain in their homes does not need to be medically based. If it were covered by insurance, there would be a lot of people who could remain independent in their own community where they want to be instead of being forced into nursing homes. That's a major push, right now. In legislation, that's HR2020. That's on-going.

FELDMAN: 2020? That's a significant number. You think about 20/20 vision.

KAILES: Hopefully, we'll be there before then. Then there's other legislation pending that re-vamps the social security system and takes away some of the work disincentives. The latter public policy in this country has a welfare mentality that makes people dependent instead of independent. It's very much of a disincentive program, instead of an incentive to go to work and keep the benefits you need.. So there's a lot of work that needs to be done. It's not going to happen in our lifetime, either.

FELDMAN: I'm afraid it won't happen in mine, but I'm still an optimist that it will happen.

KAILES: It will, but we're talking a long haul, here.

FELDMAN: Your comments about home-based care reminds me of an oral history interview we had with Elsbeth Kahn, which I was editing last week. She discussed trying to make arrangements for people at Rancho to live at home, who really didn't need to be in a hospital. But they had no way of maintaining themselves at home. She was trying to persuade the State Department of Social Welfare to make it possible for them to go home. One of the phrases that she used which struck me as relevant is that there are two kinds of people who don't do housekeeping: the ones who are very rich and don't have to, and the ones who haven't the physical ability to do it and need somebody to help them, but don't have the money to pay for it. This was the argument that persuaded Elizabeth McClatchie (in the State Department of Social Welfare) to make State funds available.

KAILES: That was in 1956. That was the beginning of the home health, in-home support services program in California. They looked at all the polio people that were still at Rancho, and they determined that if they gave each ten dollars a day, these people could be out of the hospital, on their own, functioning independently, supervising their own assistance, and not having to spend fifty or sixty bucks a day for hospital care. That was a revolution in the 50s! That goes all the way back to 1956. It was a benchmark time when that happened. That's why California is so far ahead in terms of in-home support services. But it's not enough.

FELDMAN: No, it's not enough. How else do you think we can deal with this need? I presume there are efforts underway.

KAILES: I'd like to see coalition-building, trying to build coalitions with AARP and other groups with clout to insure that new legislation re-directs and revises the current service system to make it more usable and responsive to what people want instead of what some provider system

says they need.

FELDMAN: What can the ordinary lay person do then?

KAILES: Pay attention and become more politically active and write letters and you know, the old lobby. Tell your own stories, tell how it makes life better for everyone, saves money in the end, forces people to think about their own situation. I always thought Elsbeth was pretty progressive. She seemed to understand some of this stuff. She used to bring people over to the Center - medical students - to see what the real world was like for people with disabilities. Not in a hospital where people are sick.

FELDMAN: There's not enough of that being done these days.

KAILES: No, they're not doing it now, because it was taking an enormous amount of my time, and there's no money to reimburse for the time. Medical students get zero disability contact.

FELDMAN: Since Elsbeth left the Medical School, I think there hasn't really been a replacement.

KAILES: Well I'd be glad to help. How is she? Is she okay?

FELDMAN: Not very well at the moment. I don't think we've had many social work pioneers in medical social work like Elsbeth. It's evidently something we need to have operating again.

KAILES: I was looking at the questions you sent me, and a couple of things I wanted to comment on. The question about what is your view about measures the social work profession can undertake to affect program policy that would be more or less - well - I don't think that the field of social work has played any kind of significant role in the area of disability rights. It's been a little disappointing to me, and I found the field to be - when it comes to disability, for the most part - it's as paternalistic as the rest of society. I've had several opportunities to participate in helping to change that -- NASW and some of the rest, deliberately decided not to because to

effect an attitude change is a very slow process. Life is too short, and I'd rather just decide where to put my energies to make significant change. I decided that that was not significant enough for me. So some people are pretty angry at me about that, because I just said no, I'm not going to do that. It's not going to make enough change in my lifetime to merit investment of my energy. As a matter of fact, in a lot of the work I do, social work still has a very bad image and a very poor profile in the world of disability, to the extent that it's often more of a liability to put that degree after your name than to leave it off. There is such deep-seeded resentment and anger about some of it. We know where some of it comes from. If you probe, a lot of it relates back to the medical model, a lot of it relates back to the social welfare perspective instead of an enabling perspective. It's too bad. I remember in the 80s writing a letter to the NASW newsletter, saying, look, you keep talking about minority issues all the time. You never mention disabilities. You never mention civil rights for people with disabilities. You mention blacks, you mention children, you mention Asians. I got this scathing letter back, saying disability is not a minority; it's like a medical condition. I said, "Look, I'm not going to fight this. It's not worth it. It's not worth my time. It's not going to make a difference." I walked away from it.

FELDMAN: What is something social workers can do something about? Particularly in a School like ours.

KAILES: I think there needs to be more enlightened disability content in the curriculum. I think it needs to be taught by people like me or people who come from that perspective and really present a very different kind of concept and philosophy and value system and perspective. It can't be taught by somebody who hasn't been there.

FELDMAN: For a number of years now - I don't remember the precise years - we've had several people who are clearly disabled and have had to use wheelchairs to negotiate their way

around, and some, of course, who have other conditions that I don't see. I don't know what they do in the School that could help to build awareness.

KAILES: You know, a lot of people who are new to disability or haven't really affiliated with others who have disabilities, don't come to the world of disability with any kind of civil rights perspective. That's not exactly intuitive. It's something you really need to think about. A lot of times you need some help to get to it. A lot of people with disabilities walk around this world apologizing for you having to build ramps so they can get in the building. They don't see it as a civil right. They see it as some problem within them. I think part of the issue is that there are a lot of people with disabilities who haven't been exposed to the whole civil rights perspective and are still walking around apologizing all the time - or think they have to apologize. Instead they should know that when you go into a theater, you have the right to ask for and get an assistive listening system. It should not be something you have to beg for. It's your right. Loss of hearing is a very natural condition that we all will experience if we live long enough. It's not special. It's not different. Everyone's going to have that problem, particularly our generation that puts those earplugs in their ears all day long. So it's about accommodating diversity. It's not about being special. They still think it's a favor to get a listening device.

FELDMAN: So somehow, people who have the disability, have to get the courage and the insight to make clear that they're entitled to certain rights, and convey that.

KAILES: It's not really courage. It's kind of a different way of thinking about it that comes with being around other people with disabilities and not feeling that that's going to be stigmatizing. That's another thing that keeps people away from each other. They think, "Oh, I'm not like them. I just can't hear that well." Or, "I just can't see that well." Or, "I just can't walk that well. But I don't have a disability." There's such stigma attached that a lot of people

won't affiliate because of society's misconceptions about disability. It's a problem.

FELDMAN: Now with you, your mother was able to really give you.....

KAILES: I think it was more going to college and figuring out that this didn't have to do with.....

FELDMAN: But you already had experience with her.....

KAILES: With fighting.

FELDMAN: What's going through my mind is how much our parents helped to really fight for their children so that they get into the pattern of fighting for themselves.

KAILES: You're right. The strongest role models that I know are people who had extremely strong parents. One parent sued the school system of New York City. One parent helped to sue the Berkeley campus. Strong, strong role models.

FELDMAN: Then my next question has to be - I don't know if I can make it purely rhetorical - how can some parents be reached who don't have this quality or are reluctant to use this, when you consider that that may be where we have to begin.

KAILES: For people who are born with disabilities, yes, but what about all the people who acquire - most people acquire disabilities later on? They're not all born with one. For people who are born with one, I think there have to be very strong parent-training networks, so that parents help other parents to get this. There are some parents who get this. They're natural-born fighters, and they can help other people. Basically, this is about fighting for rights, and it's not about being nice.

FELDMAN: Disabilities that come later, that are not anticipated, there would have to be another way of helping people to start to protect them from discrimination. What is it?

KAILES: That's a good question. I worry about that a lot, because I see a lot of people who

acquire disability and don't change. They just think, "Well, this is the way it is. I'm just going to have to stay home." Look, a young person who doesn't have that much - who has trouble walking - they tend to get a scooter or wheelchair. Older people - you know what they get? They get those god-awful walkers that are very unfunctional. What's that about? It's like you don't know to ask, so you don't get. I think it's a big problem. Now, the literature says that the baby-boom generation is not going to tolerate this stuff, they're going to be much more demanding about getting what they need. I'm not convinced about that. I think the baby-boom generation still does carry a lot of the same old stereotypes about disability. I think more people will demand, but not nearly enough. I wonder what's going to happen. I wonder. It really worries me. I don't know what the answer is, exactly.

FELDMAN: I don't either. I wonder whether medical associations or medical schools could prepare doctors to prepare their patients to be assertive. I don't know.

KAILES: It's not going to happen in medical schools. Medical schools are turmoil. The whole medical - that's not going to happen. We're talking ten minute hours here. We're going to have to define a whole new area of patient education where people get this in other ways. Doctors are not going to be the ones to do it.

FELDMAN: What I was thinking about is what their point of contact could be so that they would know that there should be some searching done for educational resources.

KAILES: Yes. The content and the information super highways, the internet is where people are going to have to get those skills, or they're not going to make it. Even today. If you have something wrong with you, you have to be pretty clear and sharp about what it is, and you have to research it to just oversee that what you get is what you need. So that content is going to have to become much more robust, and maybe by influencing that content, people will be able to ask for

what they need. I don't know.

FELDMAN: Do you see this whole computer age and advanced technology as a resource for getting people to understand the avenues that are available or that they ought to push for?

KAILES: Yes, I think it's going to be a major resource. Major.

FELDMAN: That really is an option that has not been so accessible before.

KAILES: Right. It's still not accessible to a lot of have-nots. There's all kinds of public policy push to make it accessible. How fast that happens and what the reality is going to be is going to be very interesting. Computer prices are coming way down, and in the next five to ten years, your tv will just come with it. There will no longer be an option. It will be part of your tv system.

FELDMAN: And younger generations will grow up with it.

KAILES: They already are.

FELDMAN: There's an advantage for them, having all this technology.

KAILES: Yes, yes. I'm very much into it. I had a nightmare a couple of years ago. Then I woke up, and I had been dreaming that I had made it all up, that none of this existed - no internet, no e-mail, nothing. I woke up in a cold sweat and I thought, what would I do?

FELDMAN: I think that is frightening. Mention your web address on this, so we have a record here. [www.....](http://www.jik.com)

KAILES: [www.jik.com](http://www.jik.com)

FELDMAN: Do you have any way of knowing how many people access that?

KAILES: Yes. This is a little counter I - I put it on later, so I don't know from the beginning.

FELDMAN: I have not yet learned, myself, how to access these things, but we have a doctoral student who does transcription on the oral history, whose area of interest is disability. I've given

him that number, so he's going to get available information.

KAILES: What's his name?

FELDMAN: Vince Ortega. He may, at some time, when he begins to work on his dissertation, give you a call. In fact, it was a question of his that made me realize that we have no material in our oral histories, or even in our archival material that deals with disability. Do you know of any organizations that have historical materials that we could have access to?

KAILES: On part of oral history interview on the ADA - they've done a whole oral history on the passage on the ADA, out of National Rehab Hospital in Washington, D.C. and have published a book.

FELDMAN: Oh, did they? Do you recall the title?

KAILES: I have it at home.

FELDMAN: Could you give me a call or send me a note. I think we should get a hold of it, too. What about organizations like the Westside Center? What do they do with their minutes and historical material? Do they save them?

KAILES: I doubt it.

FELDMAN: Do you still have contact with them?

KAILES: Yes.

FELDMAN: One of the things that worries me about newer agencies is that they don't realize the importance of preserving reports and minutes for posterity. We would be glad to have them in our archives.

KAILES: Organizations like that are obligated by law to save things for seven years. But that's it.

FELDMAN: But then they're through. Even some of the publications are.....

KAILES: Space is a premium.

FELDMAN: Do you think you could persuade them to let us have what they have, and we will catalogue it, inventory it and have it accessible?

KAILES: You might want to contact them directly. I could give you a number. It's easier for you to have direct contact. Just use my name. The current director is Mary Ann Jones and the phone number is 310/390-3611, ext. 201.

FELDMAN: I'll call her.

KAILES: Tell her we talked. You were on the board.

FELDMAN: I still get the newsletters, but they don't tell me what's happening to the materials that really are valuable for posterity.

KAILES: I get hundreds of newsletters a year. I'd be glad to save them, but you wouldn't want them all.

FELDMAN: An individual can't do that, and organizations have difficulty. We sort them - our archivist does that - and can distinguish between what should be saved and what need not be. And everything that has names of patients, we put under lock and key, or we prefer not to take. The thing that really defines how an organization started and how it's continued, I think is important. We should build up that arena of material.

KAILES: That's a lot of paper. You'd have to scan it in order to store it. You couldn't possibly store all that.

FELDMAN: Much of it is, but we do and we have it on disk.

KAILES: I think I know how to discriminate what's worth saving, and I could throw it in another box. I could clean out my files. I have a lot of that stuff.

FELDMAN: If things come to you, and you think they might be of some value, if not now, in the

future, save them for us.

KAILES: Actually, what would help me is - the only way you would get me to do this is if you sent me some envelopes with exactly who they should be mailed to and enough postage, I would do that. Otherwise, I know I won't get to it. Every time I go for a file, I clean it out. There are things that I think should be saved, but I'm not going to save it.

FELDMAN: I can understand that. I'll talk to our collector and see.

KAILES: I'd be glad to. If I had envelopes, self addressed, I'll do it. I know what's really - like last night, I looked at a document of a center. Their fifteenth year - it was their annual report, and they went back and did some interviews with people from year one - important people. This was in Chicago. Now that document should be saved. I threw it out. It's still on the floor. It's an important document. I knew it, but I threw it out.

FELDMAN: Well, keep it in mind.

KAILES: I also have a tape. What we did was - I interviewed people about the beginning of the center. I do have that tape, and at some point, I would give it up. Not right now.

FELDMAN: We could have a copy of it, if you would lend it to us. That would be good.

KAILES: I also have video. I have many videos. I have one of different views that are historically significant.

FELDMAN: The videos and tapes are very useful in teaching, also.

KAILES. Yes, I use them in teaching. I use them.

FELDMAN: Do you have a list of what you have? Could I have a copy of the list?

KAILES: I could send it to you by e-mail.

FELDMAN: Yes. Do you want my e-mail number?

KAILES: Yes

FELDMAN: I have two different ones. I'll give you the easy one. [ffeldman@usc.edu](mailto:ffeldman@usc.edu). I have that one through the University.

Are there some points you would like to make that we have not touched on?

KAILES: What significant changes have you observed between social work practice when you entered the field and today? I don't know. I'm too far away from it. I miss not having students. I'd love to have students, but I don't have the resources. But I miss that a lot. That's the one thing I really miss, a lot.

I don't think so. I think we covered it.

FELDMAN: Okay. I think it's been very instructive to have this. It will be a great addition to our oral history files. That interview guide document you have is really primarily to provide a guide to the interview, but we don't try to answer everything. It doesn't even apply to some people who are lay people.

We have just recently started to have an oral history release form. Would you be willing to sign it? You are the first person I've asked to do it!