

Stella March talks about the early development of the Alliance for the Mentally Ill (AMI) in Los Angeles....

A whole group of families had met at Camarillo, through the nurses getting us together, and we were meeting and networking there a few weeks. Some of the nurses were very good. I'm not going to give them – It's because, first of all they had, instead of a community room or small rooms, they were all, during free time, in this horrible big lobby and there were all these big guys taking advantage of the smaller ones, and it was gruesome. [And, naïve as I was at the time, I left all my son's clothing with the staff, which neither he nor I saw again.] And I think a lot of horrible stuff was going on at night, too, and stuff he wasn't accustomed to. But then they didn't have individual rooms, like of twelve people, they had long dormitories.

Long wards to sleep in and so, but the nurses were good. And we families that got together, we did meet, they got us together, all from Los Angeles. And as soon as [Camarillo discharged our loved ones,] there was nothing in the community. That's when I went to the IMDs. But what we families did in Los Angeles, [was to have meetings] at people's homes, to seek local support for community-based treatment and services through our LA County Board of Supervisors. There wasn't enough of us to support a NAMI [chapter], but we found that we had people from the five Supervisorial Districts.

So we had a good start locally to talk to the Board of Supervisors. We soon learned about that. The next step was for the State. We knew we had to get [government] funding, since it was going to cost money, which none of us were wealthy. Tony Hoffman came down from Palo Alto, from where he lived, and met us at the airport here, it was in '79. It was quiet and small. I could just picture it, we were sitting there at the airport in between his flights with Don Richardson and me and Tony and –

[Don Richardson] had two sons with mental illness. And he had been an associate superintendent of the Los Angeles school district and I knew him from the school district, because I had done some training and we had been in some of the training together. So I'd met him before and then I met him again when we met locally, when we met about mental illness. He had two sons involved; he had three sons in all, but two were involved. So he and his wife, who had been a teacher in LA County, and they both retired from that, or resigned to work for NAMI.

[We met] with Tony Hoffman to start a state organization, because we had to lobby for state funds. That's where the Board of Supervisors got their money from, so we agreed that we would support that and he [Tony] was going to have a meeting in Palo Alto, that we attended, and then he was going south to get San Diego involved. So that was set and there was a meeting in Palo Alto, up there near Sacramento, to start that group. Tony hired a woman to be executive director and the state was off. Then Madison, Wisconsin – all this was in 1979 – in Madison, Wisconsin, two wonderful women, parents and mothers, got many people from several states, because this was springing up all over the country, this wasn't just in California. It was amazing.

READ THE FULL TRANSCRIPT BELOW.

INTERVIEWEE: STELLA MARCH

INTERVIEWERS: Marcia Meldrum, Amanda Nelligan

SESSION I

DATE: May 12, 2009

I. Family and Education; With the Red Cross in World War II; Early Career in Advertising

MM: I want to start and talk a little bit about your background. Where you grew up, what your parents did, where you went to college and so forth. I understand you worked in TV and advertising, so could you tell us a little bit about that?

SM: Of course. I was born in Norfolk, Virginia, and I went to [elementary] school there, Robert E. Lee [a Southern segregated school] [she laughs]. At that time we [I and all school children] were able to walk [safely alone] to school and it was so different from today. It was absolutely harmless, no problems, no worry, no concerns [about kidnapping or assaults].

MM: A different world.

SM: Yes, it was a different world. I lived in a large three-story house with my parents and grandparents. My father was an owner [of the house] with his parents and brother. They had been immigrants from Russian Poland in the late 1880s and they came over and [finally landed in Norfolk, Virginia]. They learned English and they started a little business. At first, it was a liquor business and then, when that was prohibited, they sold soft drinks, [cigarettes and other light] merchandise. It was very difficult during those years, that preceded the Depression years. And so when I was in the 10th or 11th grade, we [had to sell the business and home and] moved to New York. My uncle, my father's only brother, had already moved to New York. My father started a little grocery business in Rockaway Beach, [where I continued my 6th grade schooling locally].

MM: Oh, Rockaway Beach, yeah.

SM: It was a different world there, too. I went to high school at Far Rockaway High and I made it in three and a half years, because it was very easy at that time and the counselor there sent [proposals to several colleges for] scholarships for me. I could only accept one for NYU and that was one I was able to do, because we couldn't afford living [expenses]; it was just for coverage of the scholarship part. [At that time, I had to live at home and travel by subway to NYU.] I went to NYU for one year and then they withdrew all scholarships, because of the economy.

MM: Oh wow.

SM: And so then I transferred to Hunter College, [still using the subways as my campus]. As an English major, I did a lot of Humanities studies and had to study a year of all of the languages: English, French, Latin, German, [to reach] the roots [of our English language].

MM: All of the roots to the words, yes, that's wonderful.

SM: And so I had a wide background there and I had a little taste for journalism. I had written college notes for the *LA Times*.

MM: For the *LA Times*?

SM: No, the *New York Times*. I was in New York at the time. I was living in Brooklyn; I went by subway to Hunter. That was my campus, carrying all my books and being knocked around [she laughs]. That was really heavy stuff, but I did it because I really wanted to. I was the first one in the family to go to college. [They were proud of me, even though not all my folks understood the meaning of being elected to Phi Beta Kappa, and graduating *cum laude*.]

MM: Did you have a big family, lots of brothers and sisters?

SM: [In my immediate family, I had] an older brother and a younger sister. My older brother passed away when he was in his 50s, because he was a heavy smoker. My [younger] sister is still with me, bless her, so we help each other. At that time when I was graduated [from Hunter], as I said, I had to refuse a scholarship to Columbia University School of Journalism, which was a big thing. However, had I accepted it, I wouldn't be sitting here today [she laughs]. That would have made a difference.

MM: A turning point, yeah.

SM: So I felt I could – first of all, my [older] brother had been – who is 6 years older than I am – had been dating somebody and was engaged and wanted to get married. He had been supporting the family, so I felt [it fair that I take over. My dad had died when I was a college freshman.] I got various jobs in public relations, [none stable], so I went into writing advertising copy. I [wrote ad copy for Westinghouse [refrigerators] at that time. That was a big thing in those years. And –

MM: This would be late 30s, early 40s?

SM: This would be in the late 30s, early 40s. Then through one of my contacts, I got an interview at station WOR in New York and I was hired there for a regular job which was good, to write copy for the announcers who needed their copy [for short interviews with celebrities, about programs, music selections, etc].

MM: In front of them, sure.

SM: I wrote all the copy and some of the commercials and that way I got to know a lot of people. [I also received] a lot of incoming releases. And after a few years there, when the war came in 1941, I received all the [federal] recruitment [announcements to pass it along to the Program Director] with PSAs [Public Service Announcements]; and then one came from Red Cross, the American Red Cross.

MM: Wow.

SM: And that one hit me, because it was [about] going over there and entertaining the troops. You know?

MM: Yes.

SM: So I applied for that and I was accepted and trained in Washington. I had been to Washington DC before; so I spent time there training and I was sent – I was never in a war zone [she laughs] – I was sent, and one of the reasons why I'm out here now is that I was sent through the exit point, actually in San Francisco – that's why I'm on the West Coast now. I was sent to New Zealand first, to Auckland, where we had troops and met a lot of people there. I learned a lot about how our troops were treating the women.

MM: Oh really [both laugh]. How interesting.

SM: Yes, they were promising them anything and everything, but-

MM: Promising anything.

SM: But not following through. [Even marriage, and going to the USA. The troops were sent from New Zealand to other war zones in the Pacific. The women were left deeply deceived.]

MM: Wow.

SM: In New Zealand, [the Red Cross] had a club house where we had dances, where we invited the local women and the troops [on rest leave.] [The Army or Marine Band] played and we served the refreshments and had some entertainment. And I always got the entertainment acts, that was my forte.

MM: You would be getting the entertainment together?

SM: Yes, and producing a little show for them. Then after that – We used to go to the Harbor when the troops pulled out and see them go off and that was very sad. I'll never forget one young man who was from Oregon. He must have not been more than 18 and he just followed me around like a little shadow, and an American. And he asked me if he could write to me when he left. I said, "Of course" and he sent me a couple of letters and then they went [makes a cutting motion]. So I still remember him. I still have very sad memories of one who was lost then.

MM: Yeah, that is sad.

SM: I learned a lot, of course, in doing all of those things and then we were transferred to another Army [base] island [in the South Pacific]. Most of the work I did was on the beach [the beaches at Noumea and New Caledonia, where I swam every morning], and that's why I have so many wrinkles.

MM: [she laughs]

SM: In those days they didn't have any sun lotion. I didn't have any lotions. I would go out early in the morning, take a swim and run back in. I didn't want to be in a bathing suit in front of all those troops. I would wake up, [arrange for] entertainment there, they sent their official band for us, and so it was a cooperative deal. So I was there. I had met a boyfriend; I had a boyfriend who was on the other side of the world. He was in Italy [she laughs], but anyway there were a lot of interesting things going on that I observed and some day I'll write about it [she laughs]. My memoirs. I signed up and was sent over there in '43 and I came back in '45, just before the surrender.

MM: Just before it ended, yeah.

SM: Yes, just before. I felt I had enough and it was just getting to me [emotionally], so I came home [on a warship carrying the wounded back home] and came in through the West Coast and that's why I – As a matter of fact before I came out here, when I went back home, there was a re-adjustment; like I can understand what the troops were going through now, and they are going through horrendous long stays. I got a job – I went back home to Brooklyn to where my mother and sister were living and I rejoined them; and then I got an offer of a job in Miami Beach, where the weather was better. I couldn't take the New York weather anymore, not after being in the South Seas. So I went down to Florida [accepting a Miami Beach radio station job, writing announcements and script and copy; the work was easy.]

MM: For the radio?

SM: Yes, for the radio at that time. So I spent about six months there and I couldn't take that anymore, the atmosphere, the culture there, it didn't excite me. [The only good thing was meeting again and palling with a cousin, who was spending the winter in Florida with her parents.]

MM: Yeah, no fun.

SM: And so I [returned home] to New York. [So did my cousin and pal from Miami. Neither of us liked the weather. And then my cousin whom I had met there, she was interested in the medical field and she came out here with me, originally to be by me. And we lived together, her family supported her. I had to find jobs and I –

MM: You came out to LA?

SM: Right, we came out to LA. I knew some people in LA that I had met when I was overseas.

MM: Sure.

SM: And I got various jobs from time to time here, not what I really wanted to do. But I did meet the man I married out here and he was from New York also. He was an architect [and had served in China] in the Air Force.

MM: Oh wow.

SM: He had been in China and had designed their airports and so he and I got together. Politically we were on the same page. It was during the [Joseph] McCarthy hearings at that time and so we really had a [she laughs] great political time together. And we were married after that, within a couple of years, in the early '50's. And then my son was born, my son, who later developed schizophrenia. And I became involved then with various organizations. I had always been involved as an advocate, an activist. An activist to really reach out politically and let them know what I thought – I had to do it – and telling other people, trying to train others to do the same. And I continued doing that with a couple of organizations in LA.

MM: Were you working while your son was growing up?

SM: Yes, I was. First, when he was young, I was doing something called endorsements. Endorsements, which I got, at that time, these movie stars out here to endorse various products like V8 juice, [Avon Products] and so on, for a few different advertisers. An [advertising] man I knew in New York had started this; he called me, it was his firm and I was hired [freelance], on an as needed basis. I got in touch with various celebrities at that time through the studios that were controlling their [publicity]. It was a lot of fun. Since I was doing that like part time, I was able to be at home and I was able to be there when my son started school. I was able to join the PTA and be active there. I became PTA president and had to – right at the time of the [school] integration.

MM: Right, in the '60s?

SM: Yes, but Burt Lancaster and his wife Norma lived right above us, [in Bel Air, across Sunset]. We lived in the same house I'm living in today; but north of Sunset was the Bellagio Road School and that's where Norma and Burt Lancaster lived, [north of] the school [and sent their kids to our public school, instead of to the private schools in the area, like other celebrities.

MM: Wow.

SM: And when they started integration, she [Norma Lancaster] wanted, since they had their kids at Bellagio, to raise money to start some busing of [minority] kids into Bellagio.

MM: Busing kids in.

SM: Yes, and [Norma started it] in that area. She was very active and we did fundraising together and so on. When [the school] had the open house, she and Burt would come over and [entertain with a performance] and so on; they were very cooperative.

MM: That's lovely.

SM: Yes, and so I was always involved in it [integration]. Just when it really [was mandated] from the Board of Education, we had a time there at that school.

Neighbors on my PTA board, [some of them] wanted me to go down and refuse to comply. That I would never do, so I lost them and I had to kind of carry on with just maybe [a few other parents] who believed with me, [while others] left for private schools. And then – that was in the mid-60s and I – Oh yes, the PTA was too confining, I couldn't deal with the bureaucracy there.

So I met with a local organization called Women Forth, in Beverly Hills; most of them were in the celebrity field. Their husbands were producers or directors or something and they were a very liberal group and they were not attached to anything. Their Board of Directors, or Executive Committee, could decide to do things like that, and that's what I wanted. So it was very good, because we had an education committee and all kinds of committees, even with the air, the pollution at that time.

MM: Right, the environment.

SM: Yes, even at that time, and also the warming, the climate; and you had some very good women who researched in each area and I came in with mental illness.

II. Development of Son's Illness; Becoming his Case Manager; Marvin Southard's Different Approach

MM: So you were researching mental illness. Now had your son [Murrow] at this time developed any symptoms?

SM: I tell you, the first time I saw anything with him was when he was in school and I noticed something about his behavior. I don't know, I don't remember the exact behavior today. But when I took him to his own pediatrician who had known him since birth, he said, "Oh, you're just a worried Jewish mother, don't worry about it, it's just a phase." So I accepted it. At that time I accepted what doctors say! [she laughs]

MM: And how old was he then?

SM: He was about seven or eight. And I'm using that [information] today, by the way, [for inclusion in the MHSA PEI component, Prevention and Early Intervention for all professionals dealing with children: pediatricians, internists, psychiatrists, psychologists, nurses, teachers, involved with children should be trained to recognize and assess possible early signs or symptoms of mental illness.]

It wasn't until he was in high school that it [my son's signs of schizophrenia] started to emerge, like most of the adolescents, at 17 or 18. [He already had passing grades in all required subjects to graduate, but] he never attended his own graduation at University High. He was political too, he used to walk the precinct with me when we were out –

MM: Canvassing?

SM: Canvassing [our neighborhood] for elections. And so he had a good feel for politics and he had worked in the Federal Building [on Sepulveda and Wilshire],

that's on the next block here. [He volunteered to answer phones at Senator Alan Cranston's office.]

He used to go there and answer phones and he would tell them more than he was supposed to [both laugh]. Because he was really very intelligent and he entered – even though he didn't graduate, he had a recommendation. There was a psychologist who was no good – at that time my husband had gone to the UCLA medical library and couldn't find anything scientifically about this illness, because at that time it [psychiatric theory] was mostly psychoanalysis. That was it.

MM: That was what was available.

SM: Yes, and we were looking for scientific views. My husband, who was an architect, was very scientific. There was no way of knowing who was doing what and at that time I didn't know it was psychoanalysis. And I think that the first psychiatrist he had was a psychoanalyst. I'm pretty sure at this point – that was so many years ago.

MM: Yeah, but it would have been logical at that time.

SM: Yes, and I think back then – and then it didn't work, because talk therapy does not work for people with schizophrenia. So we went then to – we found another doctor through another contact [who treated him with] the original medication; [Thorazine, that we know today was the first and the worst. However, at the time it did work.] And he was able to go to UCLA – Murrow was [accepted as an advanced student] in American History.

MM: At UCLA?

SM: Yes, at UCLA, and he used to walk over there or ride his bike [to class from home]. He made some friends there and he was doing all right until the second year. He played [good] tennis at that time and many of his friends were calling him to play tennis, because he played a good game. My husband had taught him how to play tennis and volleyball.

MM: So he played a good game of tennis and volleyball?

SM: Absolutely.

MM: Very athletic.

SM: Yes, my husband taught him that. So during his second year, [one morning] he was visiting a friend who lived in a UCLA dorm; I got a call that he was on the steps of the dorm and so I went over there. They took him to the UCLA hospital, to the psych unit, and I tell you, I didn't know, but at that time and even today, every six weeks they changed the interns who were studying, every six weeks. Can you imagine? With a different med and treatments that didn't work.

A UCLA psychiatrist [called to tell me that] they were sending him to Camarillo, and that was awful. It was such a hell hole. It was terrible, a whole bunch of

people, like a zoo, and they were beating each other up and everything; and my son was never violent. He was never violent and he once pushed me, and to this day he apologizes, he remembers it [with guilt]. But I really believe he started then to hallucinate just [to blot out the current horrors of his surroundings and assaults]; because today his hallucinations, hearing voices, is the biggest problem he has. [I couldn't change the situation at that time, since] my husband had cancer and was dying at the same time. He wanted to see his son, so I'd drive him up there and he was taken into the room to see Murrow. After my husband died at that time, which was in '78, I was able to get him out of Camarillo.

MM: Oh good.

SM: And I got him down to LA County Hospital which was better because it was smaller, quieter, and had good staff; and then I got him into an IMD [Institution for Mental Disease, an inpatient facility of more than 16 beds whose patient roster is more than 51% severe brain disorders]. I was his case manager all the way through the system, so I learned the system, the mental health system in LA County, first hand. And I had him at one – at the IMD, there were groups of parents who were getting together to meet with the IMD director, to give him input as to what we were seeing and hearing. First of all, IMDs had three levels of care; you had to go through – my son was always in the lowest level. You had to go down through [three] locked doors to where he was. It felt as though it were a jail.

MM: Yeah, how horrible.

SM: And we wanted, "Have all patients together and then have them treated separately." But he [the director answered], "Oh, the staff wouldn't go for it." The owner, the man, the boss, the directors, they wouldn't go for it. They were the Braswells, [the family who owned] three [IMDs] in Pomona. I finally found one called Community Care in Duarte, where the owner was there every day and made sure that everything was clean and that [all] doors were opened inside – it was locked [to the outside] of course, but everybody was able to walk [throughout the facility], and the staff did not stay closeted behind their windows.

MM: Yeah, behind walls.

SM: Yes they were able to circulate; at times you couldn't tell who was [staff and who were patients]. [All interacted well. A Community Care Center] was [and is] a more comfortable arrangement. And he tried to give good care, and that was the best of the group.

MM: So these were all private facilities?

SM: They were, yes, they were providers. They had a contract. I don't know if it was the County or the State. I think it was with the County. After that, I got him into a board and care. Throughout, we had networking through our NAMI [National Alliance on Mental Illness] organization, we have different affiliates and we all call each other and explore and share what is good, which is the best place and what isn't good. We had meetings – we had already started six or seven affiliates in

LA County; and so I found out about the CMA, which is in Artesia near the Cerritos Auto Square, right around the corner, and it's on the mall side and I took my son there. He liked it and the director said that she would take him and so he went there and he's still there today.

MM: At a board and care?

SM: Yes, and [so is the Director.] I just spoke to her before I came [she laughs], and a lot of [consumers] have [been successful] there. She has a good [facility] – I think it must have been a motel, because it's just single story [small buildings] and everything is in the open and they have a lot of open space, so the smoking group can be off [in a corner]. She has a special trailer on the property where they have day classes, right at the [far] end of the parking lot, and they have a basketball hoop there too.

MM: That's good.

SM: He did very well in the beginning. But as [staff] people – he became attached to people and [trusted them]. [After his favorite staff people left, he felt abandoned again, like when his dad died. Also he asked me many times to take him back home, but that could not happen. It really hurt me as well as him to refuse.]

MM: Yeah, that would be hard.

SM: It's hard for him. That's always been a difficult thing and I had brought in from NAMI to Dr. Southard – That's another story, with the DMH, with Dr. [Marvin] Southard. I had been working at different levels, at the federal level. I did all kinds of things there and I was on the federal board – the National Board of Directors [of NAMI] and I was doing StigmaBusters. I started that in '97 on their staff, as part time staff. I knew about all of their evidence-based programs. And when Marv Southard came to work here, I investigated and I liked the fact – I liked what he said and what he was doing. So I left – I was on at that time on the State Planning Commission, so I left, I said goodbye to Dr. [Stephen Mayberg] and decided to work down here. I thought it would be more useful, because one thing that Marv Southard had said was that he did not complain about the shattered system of care. He was the first one that I heard say, we are going to fix it.

MM: Yay, okay.

SM: We're going to fix it. And that was music to my ears because every other one -- I mean, sure, times have been tough and all we could do previously – I was always on the local Planning Commissions – all we could do was set priorities, that if we had the money, we would do this and this and this. And some of them had other – All of the directors were good people, but they didn't have the wherewithal or the kind of thinking he [Southard] has. So I introduced the NAMI evidence as proof, which he accepted, for the ACT [Adult Community Team] program, and that is something that my son is in now. It's part of the Prop. 63, the name has changed, but it's the Team Approach. That was one of the things he accepted. He bought into Family to Family education and "In Our Own Voice" education, which I am doing, and Peer to Peer [these are all NAMI programs].

MM: He bought into all these things, these programs.

SM: Yes, I brought it to his attention and the director would come in from Washington to explain it. It wasn't a matter of being a contract, it was a matter of starting it here. So it was a real partnership between NAMI and DMH and that's part of his approach to fixing it, is having the partnerships with all the other agencies and that's the way he goes, without blocks. He was a very wonderful partner and he had people at the Department of Mental Health all excited about it, the employees on every floor. I was having fundraisers to donate and so on and all of them came out for the walk and helping. Anything, anytime I need any help, I felt that I am free to call him and ask him.

MM: That's a good feeling.

SM: Yes, the feeling has been very good. I'm so glad he's still there because I'm afraid at some point he is going to resign [she laughs], but with the election coming up and everything, I think he is going to stick around.

MM: A little while.

SM: Yes, for some time, because he knows how to follow through on things, and he knows how to deal with the Board of Supervisors. But that was something else. When I first came in, we had a doctor, a psychiatrist in charge of – the director of [the Department of] Mental Health. But he was always talking – this was like in '79 and he came to us and told us all about the Board of Supervisors and I couldn't understand it at that time what the heck the Board of Supervisors had to do with it [she laughs]. I learned fast, because what we did, we started NAMI locally. We started with Don Richardson, who was my mentor, and I had worked for the Board of Education too, I had worked there in between [she laughs] in fact, and during – I worked at the Board of Education from, I think, the early '80s to the '90s.

MM: Let's stop here because you have been talking, and this has been fascinating, but we don't want to get tangled up. Let's just finish with your son, though. He has been at the board and care home, and for a while there he was being treated there? Medications?

SM: Yes, he has been treated with medications all along; one thing about him is that he takes his meds.

MM: Good for him.

SM: Well, I tell you, as a child, any time he was sick we would go to the doctor. He would get meds and he would take it, so he took it without question. He didn't question it, you see, he trusted us, and so he takes his meds. I have a very good psychiatrist for him – Dr. Steven Potkin, who is at UC Irvine, he is the director there. He had been in Long Beach, originally, and he had been a researcher at NIMH [National Institute of Mental Health], one of the original ones, so he knows a lot about schizophrenia and he worked with the World Health Organization on schizophrenia [and is also a psychopharmacologist]. He has been all over the

world giving lectures, so he knows him, and he became very interested in him and he's been with him for years.

And over the years, Murrow has been up and down, like all of them, up and down, and the ups and downs have a lot to do with [staff] people leaving, and one of the good things now, he is on the plan that has the team approach and his case manager there is a very good social worker and she is wonderful. She is great, she understands him, she has children of her own and [raised them] through adolescence. Some of Murrow's mind is still at adolescence, because what he doesn't want to do is face the years in between, the horrible things that have happened to him in those years.

MM: Yeah, that would be very hard.

SM: And that is what he does not want to face. So he goes into his hearing voices, [hallucinations]. He has found his shelter there. He just turns off everything. Even when you are talking to him, he'll move his head [affirmatively], but he's not hearing you.

MM: Yeah, he's listening to something else.

SM: Yes, and so that's the biggest problem that has grown tremendous. And a new thing that I have discovered – I have gotten to know so many wonderful people at the Department. The Department has trained about five people who have recovered, peers, to become counselors, peer counselors. Not peer to be a support, you see, there are others who are support, but this is counseling, they are trained. They had one man that matched him. He had schizophrenia and was getting to be about the same age. He's little bit younger, but had gone through many of the same things, so they sent him over to see him.

MM: And so they had a match.

SM: Yes, and they seem to get along well. They toss some baskets together and then they sit down and talk and he doesn't talk to him every time he comes. He comes weekly; but sometime he's in bed and he doesn't want to get up, for various reasons, but this is the first contact he has made with this. And he actually asked this person who comes to see him to come three times a week.

MM: Oh, that's great.

SM: That was a real biggie. That's currently getting processed, because sometimes he's ready for it and other times he's not. It depends. When I leave here, I'm going out to his place to take him for a thorough physical, because in the past three or four weeks, he lost 14 pounds.

MM: Oh dear.

SM: Because what he has been doing, he's been walking around and hallucinating, walking around the parking lot in his bare feet – and I think that had helped too, when you walk a lot; he's been doing exercises. He has done a lot of exercises too. There's an Exer-Bike they have at the board and care and he uses that too.

So many have gone through there and have gone on to live in their apartments and gotten jobs and so on. And he and a few others [have not], but they are the ones from way back, because I think that original medication did something. I don't know, but we're trying to find that out; having his complete physical to see whether there is anything physically and his doctor is right across the street, the internist.

MM: Well, that's convenient.

SM: Yea, she's very good and she takes care of all the clients.

III. Founding of NAMI; Don Richardson; Stigma Busters; SEAR Objectives

SM: So that's been a big thing, of course that has brought a lot of [unexpected friendships] into my life, [meeting many] wonderful people and through NAMI. I have friends all over the world through my StigmaBusters work. It's amazing. I get mail from every continent.

MM: Wow.

SM: There's a NAMI [affiliate] in India, NAMI India, and they sent me their newsletter and it sounded just like one of our local ones. Limited access.

MM: All the same problems.

SM: All the same problems, every single continent. I really got a dose of the world and hearing from all of these people and hearing from people who have gone through a lot of hell with their own family member committing suicide. The suicides, some of them write and say in memory of –

MM: The family member, sure.

SM: So it's been quite an educational, humanitarian time in my life.

MM: It's an amazing story. Okay, so I want to talk about how your work with NAMI developed. Okay, so your son already started to show some symptoms and you had some concerns about him and you are working with this group called Women Forth, and you said that you started to research mental illness?

SM: Yes. Now we – when he came out of Camarillo in '79, a whole group of families had met at Camarillo, through the nurses getting us together, and we were meeting and networking there a few weeks.

MM: And the main thing at Camarillo was that the facilities were horrible. People were – I mean, the nursing care was good?

SM: Some of the nurses were very good. I'm not going to give them – It's because, first of all they had, instead of a community room or small rooms, they were all, during free time, in this horrible big lobby and there were all these big guys taking advantage of the smaller ones, and it was gruesome. [And, naïve as I was at the time, I left all my son's clothing with the staff, which neither he nor I saw again.]

MM: That's awful.

SM: And I think a lot of horrible stuff was going on at night, too, and stuff he wasn't accustomed to. But then they didn't have individual rooms, like of twelve people, they had long dormitories.

MM: Oh, like wards.

SM: Yes, long wards to sleep in and so, but the nurses were good. And we families that got together, we did meet, they got us together, all from Los Angeles. And as soon as [Camarillo discharged our loved ones,] there was nothing in the community. That's when I went to the IMDs. But what we families did in Los Angeles, [was to have meetings] at people's homes, [to seek local support for community-based treatment and services through our LA County Board of Supervisors. There wasn't enough of us to support a NAMI [chapter], but we found that we had people from the five Supervisorial Districts.

MM: Oh, I see.

SM: So we had a good start locally to talk to the Board of Supervisors. We soon learned about that. The next step was for the State. We knew we had to get [government] funding, since it was going to cost money, which none of us were wealthy. Tony Hoffman came down from Palo Alto, from where he lived, and met us at the airport here, it was in '79. It was quiet and small. I could just picture it, we were sitting there at the airport in between his flights with Don Richardson and me and Tony and –

MM: And Don Richardson was a friend of yours who also had a child –

SM: Yes, he had two sons with mental illness. And he had been an associate superintendent of the Los Angeles school district and I knew him from the school district, because I had done some training and we had been in some of the training together. So I'd met him before and then I met him again when we met locally, when we met about mental illness. He had two sons involved; he had three sons in all, but two were involved. So he and his wife, who had been a teacher in LA County, and they both retired from that, or resigned to work for NAMI, and so –

MM: So you had this meeting at the airport.

SM: Yes, with Tony Hoffman to start a state organization, because we had to lobby for state funds. That's where the Board of Supervisors got their money from, so we agreed that we would support that and he was going to have a meeting in Palo Alto, that we attended, and then he was going south to get San Diego involved. So that was set and there was a meeting in Palo Alto, up there near Sacramento, to start that group. Tony hired a woman to be executive director and the state was off. Then Madison, Wisconsin – all this was in 1979 – in Madison, Wisconsin, two wonderful women, parents and mothers, got many people from several states, because this was springing up all over the country, this wasn't just in California. It was amazing.

MM: Many states.

SM: Yes, a good number of them. Don Richardson represented us – I couldn't go because my daughter was starting school at that time – so Don Richardson went and they set up an office in Washington. And Don went on to Washington and helped them set up the office. He knew how to do that, he had a very good mind for organizing, and he hired the first executive director there. And within the next several years, he worked very much with them, and also locally with UCLA with some of the psychiatrists here, working with his son and getting people to know where to go for local resources. Then we had our affiliates start; we had about at least five at the time, and that has grown of course, over the years.

SM: Sure.

MM: But the NAMI growth was started when he became President in 1986. I'll never forget, he had to rush back home because his wife, Peggy, who was at his side, was taking care of the household and the kids. She had – one of their sons had a friend who was also ill, mentally ill, over for dinner and her son hit her over the head.

SM: Oh my God.

MM: It knocked her out. Thank God, she survived and is in good health. But of course he came running back and I went over there to help too, because I lived about 15 minutes [away]. They lived in Mar Vista. When he was President, he did a great job, getting together with other agencies and other groups, and helping to start [more affiliates in] our state, and also getting together with former First Lady Rosalynn Carter. He was on her committee all during the following years –

SM: Oh, great.

MM: And he got me on the National Board, to run for the National Board, and I was on it when he was on. So I carried on at the national level, volunteering at various jobs there at the national level, after I was off the Board, because I saw the need for it and I knew what was happening at the local level and because some of the people come on the Board with very little local experience. Oh, they are going to do the world; you can't do it that way. There are ways to do it [she laughs]! So we started a campaign to end discrimination in 1995 and that's where we learned about the stigma that causes the –

SM: Ah, stigma.

MM: That's where the StigmaBusters started, out of that. And out of answering a few letters, they asked me to answer a few letters, where people were complaining. One was this Madame Alexander Doll, you remember that?

MM: Mm-hm.

SM: The doll that showed her in the shower with a dagger pointing [the Janet Leigh shower scene from *Psycho*].

MM: Oh, right.

SM: So that was my first one, and it was easy at that time. I got hold of the owner of the Madame Alexander Dolls in New York and told him about it and he pulled it. So it seemed simple, at that time it was very simple [laughs].

MM: Okay, let me just go back a little bit. When NAMI was originally founded in 1979, so what were your sort of goals? Obviously, one goal was more funding.

SM: Well yes, that was for our advocacy, but our first goal – [she laughs] we thought that in ten years, we would find the cure, through research. To work for a cure, research was the number one goal, and so the number one alert that went out for advocacy was to – We found there was one man in the Department at NIMH doing research, one psychiatrist.

MM: Wow, only one.

SM: So the first alert that went out was to Congress; everyone was to write to Congress and the Senate, asking for more money for research into mental illness. That was the very first one to go out; and many others followed, of course. We went up there; I know I used to go up every year with a psychiatrist from UCLA and visit the various Congress people and Senators, advocating for more money for research each year to keep growing; and they didn't want to hear from a psychiatrist, they wanted to hear from the family members, and so we had it each year. That was during the Clinton administration.

And of course, in the last eight years, it's kind of just stayed at the same level. I think this year, it's going to go up. Over the years, during the Clinton years, not only did we do research, but we started other things. We call it SEAR: S-E-A-R. S for support groups, E for Education for families etcetera, A is for advocacy and R is for research; so that's what we call it, SEAR. That was our goal and we are still doing that. We continued doing that and we are fortunate that our funding at NAMI National is good. They have high ratings in all of the charities that are investigated and there are grants that keep coming because of that.

MM: That's great.

SM: Yes, so we're in the black. So we have a Director that came up from the staff. When we hired an outside Director [she laughs], they wanted to bring in all their friends and have a good time; but Mike Fitzpatrick has been just fantastic. We are just celebrating our 30th anniversary this year.

MM: Yes, great.

SM: Yes, and since I'm a thirty year member, they are giving me their top award at the banquet. At the end of the year banquet, at the end of the convention in July.

MM: Okay, that's great.

SM: And Dr. House from *House* is going to be the MC.

MM: Oh, Hugh Laurie [actor on the TV show *House*].

SM: Hugh Laurie. He has come out with his depression and he has a commitment with NAMI; and so he's going to be our MC, and he's very tall [she laughs]. Anyway, I will be there, of course; and they have a whole bunch of awards and they are giving the other awards earlier at another meeting, but this one is going to be the one at the banquet.

IV. Stigma and Housing Issues; In Our Own Voice; Media Portrayals of Mental Illness

MM: Okay, so how did your concern about – how did your realization that stigma was such a big problem develop?

SM: Because of, first, NIMBYism, not in my backyard. Trying to get decent housing, apartments, and this is for people who have recovered and would have a supervisor checking in on them too. So it was impossible. We got the Section 8 passed which allows them more money for rent; but we had to – The affiliates had to train members, we had to train people to be able to go to the local planning groups, the councils, the city councils, and so on, and had to testify before them [on the housing]. Like in Santa Monica, we have Step Up on Second, which is next door to the [Laemmle] Theater there. At that time they were vigorously opposed to it at the theater. They said that they would take away business, it would be a mess, and all that. But we got our folks out to the hearings and they are there, as you know, and nothing has happened. In fact, it has increased their business [she laughs].

MM: Right, their business.

SM: Sure, and now Step Up is going on as Daniel's Place in Santa Monica, which is named after a son who had committed suicide. The family started that to deal with younger people, with adolescents, younger adults, and they are starting the third one. So now they have shown that, we have over the years in that way been getting places [opened]. And we have another apartment in Venice, that people walking by, they see an attractive building, they want an apartment, and they can't [get one]. It's discrimination against the public. It's for people who are mentally ill. It doesn't show it in any way, but it's there. They are all properly maintained. You see, over the years we have been able to, through a lot of testimony and push, have been able to get certain places built. We can show them that they keep [the building up], that they maintain it well, and it has not decreased the neighborhood [values].

MM: So you have the evidence?

SM: That's right. It took a long time to build up to it. But we have housing groups, Homes for Life, a wonderful housing group. Carol Liese is the owner.

MM: Is this part of NAMI or is it separate?

SM: No, that's a separate –

MM: Corporation?

SM: Homes for Life is a local business. It's a local provider who just builds Homes for Life, for people with mental illness, because the owner, Carol Liese, has a son or daughter, I forget which, with mental illness, so she has her heart in that. She started in the very early days. I know I have worked with her during that time too. I got to know them all in the very early stages, where we were all supporting each other, and helping to do things.

MM: That's great. So what do you think is the main problem -- the thing in stigma, I mean, is it because most people don't know very much, is it ignorance, is it the media, with their images?

SM: Well, there are several things. First of all, the misconceptions that have come out of the myths through the years and of the way that the media has treated it. The way they have immediately – If something violent happened, they immediately said that it was somebody who was mentally ill. That has decreased because our national office has dealt with the media in Washington, training them. And today they will say, after it has been determined – they don't make the diagnosis unless it has been determined, "This act was been committed by a person with mental illness off his medications." They have learned that, because it's been pounded into them through the national media, all the national newspapers. Of course you have the junky ones that continue doing that.

It was a matter of educating the public in every way we could and one of the best ways over the years, as an adjunct to StigmaBusters, has been "In Our Own Voice". That has been fantastic because the people hear and see these young men and women – They see these people face to face, telling the unique story of their recovery and are able to say it publicly, clearly. They are trained for two days.

MM: Ah.

SM: Oh yes, we train them for two days to write their story; and if there is anything very hurtful about it – they don't have to get into anything that is too hurtful for them to say – their dark days, their acceptance, their treatment, their coping skills, and their success and hopes for the future. Those five elements in thirteen minutes.

MM: Wow.

SM: That's why it takes two days, because they can write out a lot of stuff and edit down and then rehearse. That has been the biggest thing nationally that was started by NAMI. And they have a national video that goes with it, also thirteen minutes, so the whole thing takes four times that – all told, it's 40 minutes, because most of the places just have an hour to run it. And with the nurses at UCLA and USC, they have said it is just wonderful, because they only see them when they are sick. This is the first time they've seen them well and it has made

a lot of difference in the way they handle them. I set them up, I handle that too. I've set them up with Twin Towers [the Los Angeles jail facility].

MM: Okay.

SM: Sheriffs' deputies, they are fantastic; they see the results, and I get invited back and back and back. The deputies say in their evaluations, we always get them evaluated, "We have been taught to be tough, but this teaches us compassion."

MM: That's great. So it changes their whole outlook?

SM: Absolutely, and they have seen them. When they've met them in the markets or any place, they have said, "You have made a difference in my life."

MM: Oh, that's wonderful.

SM: Yes, that has been absolutely fantastic.

MM: Now, did you come up with this?

SM: No, that came up nationally. That was like Family to Family, it's part of the education [program]. This is "In Our Own Voice", and it's a national program. They did a national video which shows that it applies to every race, color, creed, ethnicity, and socioeconomic background, because they have a person on there from each background.

MM: Okay, that's great.

SM: To show that it affects everybody; to say, "We are all human beings and one in four will be affected during their lifetime." So it is spreading, and I think more good information – the magazines are carrying good information and here is *House*, with him doing this, so the TV shows have picked it up. I have fewer complaints in certain areas on StigmaBusters, I can tell by that. Because, say it's in a movie, you can't change the movie, but I will write to the producer and writer and I've spoken to some of the writers. The writers always say, "I wouldn't treat anybody that way. Myself, I have OND [other nonpsychotic disorder] or something."

MM: Right, right.

MM: And so a lot of the writers – Listen, when it hits one in four, it has to – there are like twenty thousand writers.

MM: Sure, it affects many, many people, and everyone knows someone.

SM: Yeah, that's right. So, as it gets around, and we always – With Family to Family, we send over "In Our Own Voice" to impress them and have them feel that they can talk about it, as family members, because some of them still don't say anything. You don't have to make a thing of it, but anybody in conversation can say, "My son is doing this and this...and my son is doing better. He has schizophrenia and he's taking this treatment."

MM: He's doing better.

SM: Yes, so there are ways of bringing it into the conversation. You don't have to make a thing of it, just treat it as they treat it when you talk about cancer, you see? So we give them that information.

MM: And support.

SM: So we are trying to educate the families, to talk about it naturally, and also we put it in a lot of our releases that go out nationally with that; and so I think and feel it [stigma] is lessening. I really do. Schizophrenia is the heaviest [stigma] because it's associated with violence. And of course Dr. [David] Satcher [the US Surgeon General, in the first *Surgeon General's Report on Mental Illness* in 1999, noted] that violence comes from those who are on drugs or who don't take, or are off, of their meds. So we've made a point of that and maybe – it's difficult.

MM: Yes, it is difficult.

SM: But I think we have reached them in every way we could, in the media, in the articles in the magazines, *Newsweek* and *Time* magazine have carried a lot of that, and a lot of the national newspapers, and of course *The Soloist* [2009 film about Nathaniel Ayers, starring Jamie Foxx and Robert Downey, Jr.].

MM: Do you think that's going to be a big –

SM: Oh.

MM: I haven't seen this movie, I'm eager to see it.

SM: Oh, I tell you, among the things that have happened to me is that I have been interviewed for various magazines and newspapers, and Steve Lopez [LA *Times* columnist] called me years ago and wrote a column about me, did you see that?

MM: Yeah, I've got that.

SM: Yes, because he wanted to know about NAMI, and I'm in his book. The film – we still contact each other through email and I tell you, he has been wonderful in this support for Nathaniel Ayers, he really has. The movie will move a lot of people when they see it. The other one that came out a few years ago, with Dr. Nash?

MM: *A Beautiful Mind* [2001 film about John Nash, starring Russell Crowe].

SM: *A Beautiful Mind*. But that had to do with a beautiful mind, in the fact that he was at Princeton, in that math group and he got the Nobel Prize. But then last year we had *Canvas* that had to do with a middle class family, which is very good, but it had been done on a shoe string and so it did not reach as many people, unfortunately. But it was very good, because it pointed out everything that NAMI has. It was an excellent picture, it's on DVD now. [*Canvas* is a 2007 independent film starring Joe Pantaliano and Marcia Gay Harden.]

MM: *Canvas*?

SM: *Canvas*, C-A-N-V-A-S. The writer of that picture [Joseph Greco] had called me when he was writing it, and I encouraged him to do it. He had seen his mother fall to schizophrenia when he was ten years old and he wrote a story through the eyes of a ten-year-old boy. I tell you, it was something. And then *The Soloist*, it shows the creativity, and that can happen to anybody and this man on the street, now who could be more down than that man. I want to tell you something. In “In Our Own Voice”, I have a woman who was on Skid Row, and everything in the world happened to her there. She had become one of the most beautiful people, I didn’t recognize her.

MM: Wow!

SM: She has taken care of her hygiene, she has taken care of her diet, she has taken care of everything. She looks beautiful and she is one that I always send to Twin Towers [she laughs]; I tell you, they are just special. A lot of these “In Our Own Voice” people have gone on to be employed full time. I have to keep training more because they have made it, which is a wonderful thing.

MM: That’s wonderful. I mean, it certainly presents more hope for the future.

SM: That’s right. That’s right. I think *The Soloist – The Soloist* in the first three weeks has been up there in the first ten. Last week it has been number seven and number six. I get a lot of email from all over the country saying, “Oh, I’m going to see *The Soloist* tonight.” [she laughs]

V. Daughter’s Work in Art Therapy; MHSA; Importance of Early Intervention; Working with DMH; NAMI Goals v. MHA Goals

SM: I have a daughter too who has been impacted. My daughter is younger than my son and she is an artist. And what she did, I didn’t even know about. Thirteen years ago, she walked into a shelter for women in Santa Monica, women who were on the streets and who were being transitioned back to the community. She wandered in there and offered to do art therapy. She’s an art graduate of UCLA, she’s an arts major at UCLA. And so she didn’t have them just paint in between the lines. She taught them the real art and she saw some real talent come out, because she can envision it, see it. She’s an artist. She puts shows together, she does art, she teaches, she curates, she does everything.

MM: Oh, good for her.

SM: And she has gotten, over the thirteen years, she has gotten occasional grants. She has made it up to where she includes all of the arts.

MM: Oh, wow. That’s great.

SM: DMH, I told them about it, so they have her in two clinics. One in South Bay and one in South Point, or something like that, at another clinic, two clinics, and they are so pleased with what she has done. She has poetry, music, dance, improv, art –

MM: Everything.

SM: Yeah, all that for the clients to choose from in their Wellness Centers. So she is having a struggle, getting more grants, because she and all of her staff – they are all professionals who do this; and she has to pay them for that and mileage, because they don't get any benefits, it's just like a job that comes in timely. So that was a definite impact of her brother's illness.

MM: That's great.

SM: Yes, and I didn't even know she was doing this.

MM: She didn't tell you.

SM: She found it herself and I found out later. And I introduced her to people at DMH to get a grant, and they saw it was worth while, when there was money available there [she laughs], but you know you can't count on that.

MM: No.

SM: So we are trying a different direction now, so that's the story of my daughter.

MM: Okay. You spoke a little earlier about working with Marv Southard; and sort of understanding the new approach, the Recovery Approach, and this has obviously been – it's not exactly new, but it's certainly been much more developed in the last ten years.

SM: Oh, yes, definitely.

MM: So can you tell me – I mean, this was not something that was available to your son, it sounds like.

SM: The only thing – in the past ten years, getting it started took a couple of years [she laughs], and the money didn't come through until, I think, '04 or '05.

MM: '05. Sure, with Prop. 63.

SM: And that's when the ACT program was put over. That was the transformation. The Team Approach that was used, that was one of the first components, was to have the Team Approach and they called it – there was a special name for it, but it had to do with those who were the most severely mentally ill. That was the first go around and that was the Team Approach, and he's in it.

MM: Is that FSP, or?

SM: Yes. That's FSP, Family Support Program. That was the first component to go through. I have been on the committees, the SLT [System Leadership Team], and the Stakeholders. So I have been bringing the knowledge I have at the grass roots, also seeing the residents at his board and care. I talk to all of them, and hug them, and so on, and they all greet me, because I go out there every

Sunday to take Murrow to lunch. They are a wonderful bunch and a lot of them don't have families or anybody visiting them.

Anyway, the ten years has to do with – Marv [Southard] came in in '98, and this is '09, but the money didn't come in; but his work was the Comprehensive – he started first with the Comprehensive Community Care. He came in with the idea to fix the system, to make it the best program for as many as possible. That took a couple of years with a lot of committees doing different pieces of it and then he started that in '02 – Comprehensive Community Care, the CCC program. That was picked up to be part of the Prop. 63 ballot. What was on the ballot was the CCC mission.

MM: I see, okay.

SM: When I read it, I couldn't believe it, and I called Marv, and I said, "Marv, am I seeing something, is this really it?" and he said, "Yes, it is."

MM: That's wonderful.

SM: That's what the legislature wanted to use, and that did it. That was supposed to be the mission, of course, but when they re-wrote it legislatively, they changed a lot of it. You know, what you put in the thing, the legislation somewhat changed it, but they got the meat of it. One of the go-rounds that is very important is the prevention and early intervention. Early Intervention, I'm very big on having everybody train that deals with – like pediatricians, nurses, everybody that deals with children, to be able to recognize possible symptoms and to investigate. I've made a big thing of that and I've picked up other things that I have proposed for those programs, because Early Intervention is so important, because that could save all of this money in later life and save lives.

MM: And you did research on this?

SM: Huh?

MM: You did research on the Early Intervention?

SM: No, I just gave my input about my son, that he is not the only one that this happened to.

MM: Where there was no Early Intervention.

SM: There was no training.

MM: Yeah.

SM: Nobody knew how to recognize it, you see, they have to recognize the symptoms and then investigate it. They may find that it's just a phase or they may find out that the child has an illness – but they know how to do that now, over the years they've learned. But the thing is, it has to be extended to all of the professionals who deal with children – the nurses, the psychologists, everybody that deals with them, to be able to recognize certain symptoms when they see them.

MM: That's crucial.

SM: Yes, that was one of my proposals there. I put in other stuff that I've learned over the years, as the components come through, and I know and have observed a lot. I have listened a lot. In my first years, I didn't say a word, I just listened. I don't give big speeches now, but I just try to get to the point of what seems to be good and what seems to be workable, based on how much it would cost, the cost effectiveness.

MM: Right, because that's always an issue.

SM: Yes, we have to deal with that. Of course right now with the election coming up, oh boy. The minute you get something –

MM: Yup, they take it away.

SM: That – Well, I won't say.

MM: [she laughs]

SM: Actors don't make good governors.

MM: No, probably not.

SM: [she laughs] I feel that we were well on our way to really doing a lot of good stuff. I know in LA County, Marv had a lot of other ideas too, that are on hold and the local budget is in bad shape.

MM: Yes, I know.

SM: Because of the economy.

MM: Sure, sure.

SM: Because so much of their money comes from sales tax.

MM: Right, and all that is going down.

SM: So right now I'm facing committees that are dealing with deficit mitigation [she laughs].

MM: I know, it's horrible.

SM: Yeah, so it's been up and down, and around, and up and around, here's where we started.

MM: So you are a Stakeholder representative to the MHSA?

SM: Yeah, and also the SLT, which is the System Leadership Team. In other words, the Leadership Team originates the ideas that go to the Stakeholders and they

have to be passed by the Stakeholders and then it goes back to Dr. Southard's group and the Leadership group and then to the Board of Supervisors and it's up to them. And of course the State is forever sending back new guidelines [she laughs].

MM: Yeah, new guidelines, so there are always something to react to, or to comment on. How did this relationship develop? Were you always able to give input to the Department?

SM: Yeah, I worked with all of the – I worked with all of the [Directors] on the planning, with Dr. Roberto Quiroz, who was there in the '80's, and –

MM: Dr. Crowell?

SM: Oh yes, Areta Crowell. I worked on their planning committees, but it was not as exciting as this [MHSA] is, because it has money [she laughs].

MM: Makes a difference.

SM: It makes a big difference, because there wasn't very much – they did the best they could. I know, with Roberto, we were constantly making up priorities [she laughs], where at each meeting, we'd redo our priorities. But Areta was able to get a few things through. But this was exciting, because it was a glimpse of the money. I hope that continues.

MM: I hope so. Yeah, so [pause] – I forgot about MHA, have you worked with Mental Health America, Richard Van Horn's group? Have you worked with that?

SM: Oh yeah, I've worked with Richard Van Horn. I had worked with him many, many years ago, before NAMI was started, and I have been on his committees, I know Richard very well. Yeah, and I see him at the meetings.

MM: How do you see these two groups, his group and your group, working together?

SM: Well, I tell you –

MM: Does one of them do which one –

SM: Well, Mental Health Association is a provider [of treatment and services]. NAMI is not a provider. We are a volunteer group and we look for providers to do the work, and so that's the difference. [NAMI is a grassroots family and consumer association with SEAR – Support, Education, Advocacy, Research – as its goal.] That's a big difference.

MM: Yes.

SM: In other words, I didn't feel that I could go on his board – I didn't have the time anyway. He wanted me to be on his Board of Directors and I felt that it would be a conflict because he is a provider and I wouldn't go on any provider's Board of Directors.

MM: No, no, that would be a conflict of interest.

SM: Yes. But apparently they consider themselves more like us.

MM: Yes, that's what he said. He said, "We are an advocacy group." That's what he said to me.

SM: They advocate, yeah, sure. Well, all groups advocate. I think all provider groups advocate. They advocate for [the funding we all need, along with them. On the County level, we work together on our joint principles for advocacy, legislation, etc.]

MM: For what they need as providers?

SM: Yes, as providers. He does a good job with what he provides, [especially helping consumers find employment]. But the thing is, is that the Village is not a housing entity. [It is a full-service clinic. They have a team who visits their clients, wherever they live in the community.] People are confused. The Village, they think, is a living place, [but] it's a clinic. It's a clinic, period. There are a lot of misconceptions about that, you see. Other providers have not gone to that extent of the media that they have been given; but they've picked up a lot of the stuff that we do [she laughs], which is okay. We're doing our thing.

VI. Housing; Lobbying; Henry Waxman; Mentors and Influences

MM: When you first started, better housing seemed like one of the most crucial issues, do you think? When you first started NAMI, you identified more funding?

SM: Yes, we had. Research was the number one thing.

MM: Yeah, that's what you said.

SM: Then housing.

MM: Then housing, okay.

SM: Because the advocacy was obvious. We had to advocate first for the research. We had to get more than one man on research immediately and then we started housing. And that's when Carol Liese and I and some others got together in Santa Monica, where she lived, and we were talking about how to get housing started and she got a developer and some money. She hired somebody to help, a grant writer.

MM: Right, right.

SM: She was one of the original starters. There are other groups now that –

MM: That provide homes, yeah.

SM: Yeah, they construct or they reconstruct. That was the second one. The Education, of course, was internal: [Family to Family, In Our Own Voice, Family

Basics (Families with young children), among others.] We didn't have to go out for that. The fourth was Support, which we did ourselves, so the two big advocacy things were Research and Housing and money [she laughs], funding.

MM: Have you been involved in lobbying for many of the legislative things? There was AB3777, which is the one that supported the Village, have you been involved in lobbying for –

SM: Well, I've gone out and lobbied and testified over the years for all of the bills that would help, all of them. Any of them that would – I used to go up to Sacramento a great deal to lobby directly and to meet up with our representatives. But then we have more influence with our own, so I usually meet them now in their own offices. I don't like going up to Sacramento anymore, because you spend three hours, with the security. It's an hour trip and you have to get up early, to get through security, and then you come back, it's another hour. So it takes three hours for an hour trip. I'd rather go across country because at least you are getting someplace.

MM: Sure, sure.

SM: So I usually lobby directly in my own office. I know a lot of them that I have met in the past, who have been [helpful]. I'm always watching that, and NAMI sends us all the national bills that we have to be on top of, with our Senators and Congress people, and [Rep. Henry] Waxman is marvelous. He's my man. Back in '88, I went to his office in Washington and he sent me to his staff, to give me all of the information about the [legislative] funding of Medicare, Medicaid, and the state grants, the state block grants, and I learned all about that, directly from the source. Of course in '94, when one of his staff and I had written just one paragraph about the IMD exclusion, things fell apart. In '94, the Republicans came in, and we were about to introduce that. Now we're still fighting for it, that's another one we're testifying for, the IMD exclusion, which is so stupid. We almost had it. But I've learned so much from him and Henry knows me well. [Federal Medicaid matching payments are currently prohibited for IMDs with a population between the ages of 22 and 64.]

MM: Yeah, he has always been very supportive.

SM: Yes, and I have to go see him one of these days [she laughs] down in his office here. He's a good man. He stuck it out and he's back in his original thing now.

MM: Good.

SM: Thank God, he's back in charge of that strange committee that gives him Mental Health [Waxman is chair of the Energy and Commerce Committee, which includes the Health Subcommittee]. Because we need that these days, and he understands. I just wish they could get the single payer [health insurance] through. I've found that Medicare has been absolutely fine. I've had no problems with anything I needed on Medicare. I have AARP with it, the Supplement. And anything I've needed, I've been able to go to my own doctors; I have my choice of my doctors.

MM: That's great.

SM: I've kept the ones that helped me before and they are willing to go along with it. They say with single payer, you have to wait to be seen -- well, you have to wait for the other doctors, too.

MM: You always have to wait.

SM: Sure, doesn't make any difference. The insurance companies are the ones that they've already had -- they contracted my son's Medicare. He's on Medi-Medi. They've contracted it out to Blue Cross, Anthem Blue Cross, yes that's what the Bushes did. They are under contract.

MM: That doesn't work as well?

SM: Well, so far. I'm watching it carefully. He's getting everything he needs. If they turn him down or anything, believe me, I'll open my mouth [she laughs].

MM: Yeah, that would be that. Let me just ask you one more question.

SM: Sure.

MM: You mentioned Don Richardson, is there anyone else you would mention who was a major influence on you or helped you understand things or showed you how to do something?

SM: Well, I think he was the major one. He was really the major one because he started it and went on for about 10 years. And before he passed away, I went over to visit him. I visited him and he always wanted input about what was happening during his last days; and he had the greatest influence on me. And then Dr. Southard has. I feel both of them used their brain [to be solvers, not whiners].

[Also, Representative Waxman and his staff, and the legislative directors at NAMI National who took me through the US Capitol, including its most underground tunnels and subway, as well as the policy making at the national level.]

MM: That's important.

SM: Using their brain and heart with the brain, and doing the right thing. And Obama is the other one [she laughs].

MM: He certainly has a brain.

SM: He knows how to speak.

MM: Okay, we are going to conclude this interview for now.

SM: What time is it?

MM: It's about five minutes after twelve.

Duration: 98:25 minutes.

Session II May 26, 2009

VII. MHSA and the System Leadership Team; Housing and Siting; Importance of Federal Match for Case Management

AN: We wanted to know your feeling about Proposition 63, and you said you were involved.

SM: Oh yes, very much so.

AN: And you also alluded to the fact that it changed a little bit from the original conception, so if you could just say more about that?

SM: Yes, I had been volunteering on various levels; and I had been on the State Planning Commission since 1998, when I learned about Dr. Southard. You know about him, he came back here, he had been here originally at El Centro, and I met him in 1981, when he was running a Spanish-speaking group.

AN: Wow.

SM: And he invited me, and Don Richardson, who was also part of this, and his wife Peggy, to work with him on [developing] Family Support, and so on. So, when he came back, and I knew him, and I heard about his vision, I dropped the State [Commission] and I came here because I felt that his vision – He didn't come in whining like all of the others saying, "We have a shattered system of care, it's no good, we need money, and blah, blah, blah." Instead of saying that, he said, "We're going to fix the system." That got me. For once, someone is going to do something positive. And he led the way, and he had a vision called CCC – Comprehensive Community Care, which just hit the spot with all of us. We were teamed off and I worked on the Team Approach, which was the ACT Team that NAMI has, and I have since brought in all of the NAMI programs [she laughs], which are good, they are all evidence-based.

Then, after a year of the teams working on different aspects of community care, he called a halt and [said that] we are going to integrate this. We integrated it and we were about to start it. We didn't have the funding yet, but we were about to start some pieces of it, that he was able to garner with some money – some funds he found from retirees, or whatever.

Along came the idea of the MHSA, Prop. 63, and we all worked hard for it and it passed. And I had read in the introduction to Prop. 63, and it was the exact copy of the vision from CCC, that had passed. And then the State took over, because before that, the money from the County had come from the vehicle license patent. This way it goes through the State, so they set up a bureaucracy of oversight and all kinds of sight and all kinds of guidelines that they repeatedly changed. [You] start doing something, send it up there, the changed guideline comes back, goes through the Board of Supervisors, back up there, back down again, so it took time. But our first component, which was Community Support

Systems, CSS, went through and they used the Team Approach - FSP – Family Support System, and it worked. It's really been doing very well. The outcomes are good.

Before we got that, we couldn't do anything. We sent the proposal up, getting it through the Board of Supervisors, the usual discussions and changes, and actually they tried with the two groups – we have the SLT – the System Leadership Team – and the Stakeholders, which is the larger group representing all the agencies. I have been on both since the very start. So I've been going to all the meetings. I go as a representative of NAMI Los Angeles County, representing the whole County. [The] NAMIs, there are about 12 groups but my vision is very – I mean, I just totally support Marv's vision because it's for everybody and I'm not just thinking about NAMI in this respect, it's for all the people, all the clients, and I was very pleased with the way it was working. It really was getting consensus, it was very transparent.

AN: The delegates? The System Leadership Team? That's what you're—?

SM: Yes.

AN: Okay.

SM: The System Leadership Team actually started a year later. That was after we had, not problems, but the [issues] that had to be kind of ironed out before it went to the Stakeholders. So the System Leadership Team would get it first and we would mull it over, and in certain instances we could dispose of it or approve it without [it] going to Stakeholders, depending on what it was. Now, to save time, it was a smaller group because the Stakeholders group was well over a hundred, representing all the agencies and everybody – and before, did I tell you the discussions and the repetitions [went on] over and over again? The same question over and over again and it was really time consuming. They usually ran for five hours. The System Leadership Team took three hours with about – we have now – It's gone up to, it started with 26 people and now it's gone up to about 40 people so, and even then it's now taking longer because people have –

The thing is, we wanted System Leadership Team to become constant, to have the people come regularly so you don't have to backtrack and get things done, because Marv was always saying, "We've got to go and get it now." You know, not to wait, to get it done and always trying to get consensus. And that [the Stakeholders group] held up a lot, because some of the people have their alternates there and some of them didn't understand and because they hadn't been, [since] they had been in just a little piece of the system. I had gone through the entire system as my son's case manager. I had gone through every piece of the County mental health system, so I knew what was going on in every place.

AN: So what would you say is the best thing that the Mental Health Services Act has accomplished? If you had to pick what the best –

SM: Well, I think the FSP, so far, but they have completely excellent ones following. There's the money for the housing, which is still in limbo. The housing is the big problem.

AN: So can you say more about that?

SM: Well the housing, first of all, on Skid Row. Steve Lopez [she laughs].

AN: Yeah.

SM: It's so true when the people there can use the housing, the appropriately built housing, with supervision and help. It's kind of targeted for them, they need a different kind of supervision and help than people that come from homes on the Westside. It has to be individualized and so [it's] going into areas and finding sites for housing or buying homes to re-do, to reconstruct, rehabilitate. Not the stigma. They don't, they won't –

AN: They don't want to rent to –

SM: The County won't allow it.

AN: I see.

SM: And the neighborhood won't allow it. They get wind of it and say, "not in my neighborhood..." NIMBYism. So that's been a big, [it's been] one of the biggest things and of course the cost of housing has gone up, so they can't get as many [housing units] as they would with the money that was allocated a few years back, before the cost has gone up, in construction, everything. So, lots of problems there, but they will be overcome. I know that there's going to be a nationally known speaker on siting, Debra Stein. I just heard about it and I sent in my registration and there's still room. I think it's June 1st, under the auspices of the Department of Mental Health.

AN: There's still room? Okay.

SM: Yes, so many things going on.

AN: That's good news.

SM: So the housing, and so they are bringing her in to see what suggestions, or recommendations she could make, because she's a nationally known person, I understand from Marv's letter. Now, the P-I-E, we call it PIE [she laughs], Prevention and Early Intervention. That we just went over the other day in depth and it looks like it's going to be approved, or parts of it have been approved, so they can start on it fairly soon. Now, everything was waiting for these initiatives [on the May ballot].

AN: I know, what do you think of that? I wanted to ask you about the elections.

SM: Oh yeah, I was thrilled because we supported, we were for "no, no, no, no," [voting no on all the ballot initiatives] and we did a lot of publicity on that, among

our people and their friends and told them to get absentee ballots and so on. We did the usual [all laugh].

AN: You were very successful.

SM: Oh yeah, and [what happened was] that all the organizations, the state organizations, who treat mentally ill people formed a coalition in Sacramento and sent to their own people the information, so it wasn't just NAMI at the State level, it was the Mental Health Association, the Mental Health Director's Association, Hospital Associations, all the people that do work for them, that have them as their clients. They did not want to lose it [MHSA] and another good piece on top of it. Federally, a year ago, they were rescinding the co-pays on case managers, on targeting case managers, who are the most important part of the whole plan, and good old [President] Bush had them [HHS] want to get rid of that, get rid of the co-pay. They shared dollar for dollar.

AN: Oh, I see, yeah, the Medicare Match, the Federal match.

SM: Yeah, it's the Federal Match on MediCal, Medicaid for case managers.

AN: For case managers.

SM: That [was] for his big time people. He also got contracts for Anthem Blue Cross, that's now in charge of some of the Medicare and Medicaid. That's something else he did, bringing in those big companies. That was all done in the past, just before the election. Just the other day, that targeted case manager [provision], we did manage to get that held over for a year, because we knew there would be a new election and Obama rescinded it. So the case manager stuff is –

AN: We didn't even hear about that, I mean that was not –

SM: Yeah.

AN: Wow.

SM: Because our National NAMI was right on top of it, on these things, on these specific [issues], and so were the other national organizations. But I got the news directly from last week, that he signed that, so we still have that match, thank goodness, because that's a basic part of the FSP.

AN: Yeah, that would be devastating. I mean, most of their [the clients'] contact is with case managers.

SM: Of course, they're the ones that run the whole thing.

AN: Right, because they are not really needing therapy.

SM: They are really excellent. My son's case manager, because he's in FSP and is on the team, and that case manager is magnificent. She is excellent. They all are so caring; and so that's been very successful. Now, on the PIE, one of the things that I suggested, right off, [is that if] you want to prevent mental illness –

You have to recognize the symptoms when they are young [taps desk for emphasis]. And this is based on my own experience because when my son was 7 or 8 or 9, in that area, I noticed certain behaviors. I don't remember what it is today, because it's too long ago, but I noticed something. And when I took him to his pediatrician who knew him from birth, he said, "Oh, you're a crazy old Jewish mother. It's just a phase, he'll be fine." So at that time, I accepted his word and what happened in the second year of college – the last year of high school, the second year of college, it [her son's illness] happened.

So I immediately said the first thing I want to see in this, and I put it through and I'm going to harangue them until they get it in, [is] to have all the people who deal with children in schools, from the psychiatrist, the doctor, the pediatricians, they have to know, the nurses, the psychologists, everyone who deals with kids have to be trained to recognize symptoms.

AN: Sure.

SM: Have to be; because how are they going to prevent it? I mean, your basic thing is, you want to prevent it [she laughs]. You have to recognize the symptoms and prevent it. When they are kids, you can prevent it and they are doing wonderful research on the kids, wonderful research is going on. So they can recognize certain symptoms and they don't have to fill them with meds, but they may have other ways.

AN: Sure, if they could see it early on, they could do other things.

SM: They could deal with it in other ways, so they don't have to take those damn meds. So I think that was just to me the main thing with PIE. There are other parts of it that are – They are all very innovative and very good pieces. They put together a good program and I think part of it is, has been approved and the money will be coming in soon, because it was on the assembly line, waiting.

AN: Right, I've seen that the other Counties have already had their packages approved, so L.A.'s almost done, that's good.

SM: Yeah, right. We had parts; I think parts of it have been approved. So now the money will be coming in and then there is the infrastructure, the buildings – and the expansion of the computers for all the [information] to be exchanged, because these people move around through the state, and all of the computers, even intra-county, have to be increased.

AN: Right and they don't. They don't know. They don't talk to each other.

SM: That's right, so all of that has been planned with the money in the infrastructure.

AN: Oh, wonderful.

SM: Yeah, to expand the computer size. Of course, I don't know the technical language, but it's to expand the computer to take care of all of those areas where they can be reached by wherever the client happens to appear, whatever the client has had –

AN: So you can get all the clients' records and charts. It makes sense.

SM: Immediately, and not start from day one. The other thing is the building itself. I think right now, I think, underway is the new headquarters building, somewhere in central Los Angeles, because the staff with this has increased, obviously.

VIII. Directly-Operated v. Contract Clinics; NAMI Programs; In Our Own Voice and Stigma Busters; Vision for the Future

AN: Okay, I just wanted to follow-up on a couple of things that you mentioned last time. I guess you were talking about Richard Van Horn and Mental Health America and you said something, which I thought was very interesting, about they are good at lobbying for themselves.

SM: Well, sure. Everybody does.

AN: Well, I was wondering if you had more thoughts about, because we have been asking a lot of people what they think about the directly operated clinics versus the contract clinics and how they see that relationship. So I wanted to hear your thoughts on that as well.

SM: The directly operated?

AN: The County-run.

SM: Yeah, I know the difference. We are able – Dr. [Marv] Southard is able to directly change various things in the directly operated clinics. He's the one in charge. Rather, Dr. [Rod] Shaner [DMH Medical Director] is as far as – For instance, he got them to watch for obesity, that leads to diabetes and to have them go to an internist, to go for physical health when they recognize certain symptoms; and he introduces various things on his own that he can, in the directly operated.

There are a group under contract and the head guy of, I've known him for many years [Bruce Saltzer, Executive Director of the LA County Association of Community Human Service Agencies (ACHSA)], he's at all of the meetings and speaks up very loud and clear about what they want, which is true. They really have, I think, there are like 20 some directly operated clinics and there are like 80 on the other side [contract]. They have at least twice as many [clinics] and so they are a very important group and Pacific Clinics does an excellent job. They are tremendous. Hillview does a good job. There are certain –

AN: Certain groups that you think are doing good work?

SM: And others need more help. It all depends on who is running them.

AN: Sure.

SM: And so the directly operated have clinics out in Antelope Valley and not to Malibu, but to West Los Angeles and to Downtown. So they have good coverage and they have a good one in Hollywood, too. The Edelman Center [in West LA]

is good. They are all good clinics and if they are not, we get the – I get family complaints. They call me and other family leaders, and tell them, and when we tell Dr. Southard about it or Dr. Shaner, they do something. They follow-up and they ask – Now with the contract clinics, we don't get too many direct calls on them. They take care of it directly. They go directly – they know where to go.

AN: Okay, so you have a stronger – well, tell me if this is correct – you have a stronger association with Dr. Southard and his clinics and less –

SM: Well, there are a lot of subcommittee meetings and I'm on many of those too. And so is – what is his name?

AN: Richard Van Horn?

SM: No, the one who's the head of the county group of contract clinics?

AN: The lobbyist, Bruce?

SM: Bruce, Bruce?

AN: Bruce Saltzer?

SM: Bruce Saltzer, yeah. He's at all the meetings.

AN: Yeah he is very vocal.

SM: Yeah, and he talks and talks and talks [she laughs]. He speaks up for everything that's going on there and makes sure that they get their share. The money that comes down, there's a split. They get so much, and the directly operated get [so much]; and obviously they [the contract group] have more clinics, so they get more money. I don't think they have any trouble in that area, but he speaks up like on the WET committee.

AN: Workforce Education and Training?

SM: Yeah, I'm on that committee too, because we want [funds for] training for our Family to Family and In Our Own Voice, which I also do introducing, which is the best thing for stigma that ever happened and the Peer-to-Peer; they do clinical training and they can go to the contract clinics as well and so we want – so I'm on those committees to see that we get our dibs in on training for these also, that are evidence based programs and cost money because they run for a couple of days. I get it for In Our Own Voice, which is a two-day training [program], and they do a fantastic job over at the Twin Towers and they have educated and informed their sheriff's deputies. They've gone back, they've been invited back at least six times to reach all of them and in the evaluation, I got this by mouth by one of them: that they are taught to be tough, but this taught them compassion.

AN: That's wonderful.

SM: That really made that whole thing worthwhile and I had met the head of the training at DMH, the head of the training for the Sheriff's Department, and I had been on the panel with [Sheriff Lee] Baca earlier on. So I'm after them now to go

to the women's division -- they have a special women's center and also, all over town, they have sections, and their Academy – to have them do it there. I've also set up with Probation, for their offices, they are going to go into a twelve week training this summer and they're going to have it every week.

AN: Great.

SM: So that's something done with our cooperation, because they really do the best job. The attitude changes there, the behavioral group, the national study –

AN: We should take it.

AN: Yeah, yeah, you should.

SM: I'll let you know when they will be presenting.

AN: Yeah, I'd love to see that.

SM: Yes, and they go to the Family to Family group; Family to Family has 12 weeks of training; and on the eleventh week they always have a client and so they are now taking the In Our Own Voice.

AN: Oh, okay.

SM: For their training.

AN: Oh good, that's great.

SM: Yeah, because, believe me, we find it [stigma] in families, in clinics and it's because Dr. Southard has said that he wanted every clinic to have In Our Own Voice. They each had to take it, [she laughs], because there are plenty of stigma among the professionals, plenty. And I've gotten complaints from some people, from clients who had been hired by the Department and whose supervisors were not treating them properly and I said, go to see Dr. Southard. I'm not part of the Department, I can't do anything, but I can tell them what to do. He got after that, and he had one woman changed out of that group, but he's watching that group [she laughs]. He knows what's going on all over the city and all over the County. And she is now in a situation where she is doing very well.

AN: Oh good.

SM: Yeah, because here we go after the outside world and tell them to employ these people and if the department can't employ them, how can we go out and tell them? Yet the In Our Own Voice people, I have lost a lot of them to employment outside.

AN: That's a good thing.

SM: Yeah, so I've lost them, so I have to have training every year.

SM: Right, new people.

SM: It's a two-day training, getting more people. The first group, it's really quite something. This is a volunteer job [she laughs]. But I love it; I think they are just wonderful.

AN: Well, I would love to see it. Well, that's really all of the questions I have. I guess I was thinking, you've spent – You've been dealing with this basically almost your entire adult life since your son –

SM: For thirty years.

AN: For thirty years, and [you] have been an advocate and working so hard to change [things]. If you could imagine everything that you are doing, being successful and really the environment, the world changing, what would it look like? Like, what is your ideal vision of how we would all live with people who have mental illness? Can you tell me what that world would be like?

SM: Well, there are various facets of it that I deal with in Stigma Busters, because I'm on this national staff with Stigma Busters Email Alert; and I hear from people all over the world and in every continent. They have the same illness, they have all of our products, our ads, our publicity, our movies, our TV shows. All of them go around the world with the illness, so it's the same. I have seen a newsletter from India and it sounded the same as from one of our local ones. We would [like to] see enough funding; they need the same things; they need funding for community care [and] outreach for those who are uncovered, who are not covered or not receiving any benefits. So, when you ask me what I'd want to see, this would go for all over, for what everybody needs – it's access to the treatment and services they need with the required funding.

[Also] the lifting of all stigmas, of course, [and] the complete elimination of discrimination, the community understanding and receiving them in the community as a normal citizen, and allowing them to find jobs for which they're qualified; and there's some who are PhD's and some who have gone back to college. Because you see, mental illnesses have three levels: the low functioning that go on, like my son happened to fall into that category. There's a middle range that recover to their limit, and do well and they have relapses from time to time, for a short time, and then they come back. Then there is a top group that has it once and never again. These, I believe, are the clients that are the most vocal today and are positioned on anything. They don't realize how lucky they are that they had it just once. They are so vocal and they speak so clearly. Everything is there and they don't realize that and you can't tell them. In the best possible world, all of them would be able to reach that level, maybe at least the mid-level, and there would be enough there.

Actually, I know from NIMH, they are on the verge of reaching [that goal], through the advanced system of brain scans. They have been scanning brains for years, but there are improved scans now and they are looking [at that], and they expect to find the exact piece or point in the brain for each illness, so they can individually treat the person.

AN: Wow.

SM: Because right now it's – the medications are trial and error.

AN: See what works.

SM: Yeah. So that would be just remarkable. The head man spoke at our convention and he said that, and he also said that they expect it to happen within five to ten years.

IX. Medication Issues; Son and Daughter Today

AN: So, did I hear you correctly, do you think that maybe, like if your son was a teenager today and the symptoms had been recognized as early as possible, do you think that low functioning people, as you described him, have a chance of being in the mid-range? Can you say more about that?

SM: Yes, because the medication he originally received was that awful stuff, back that they used at the state hospital.

AN: Was it Haldol [haloperidol]?

SM: No, it was –

MM: Thorazine?

SM: Thorazine. It was horrible. You see, my son, we had taken him to a pediatrician anytime he was ill and for check-ups, and he always took his meds. It was a natural thing to do, so he took his meds. So when he got it, he didn't question it. And that Thorazine, I think, is what may have destroyed a part of his brain; and at that time, nobody knew it. Psychoanalysis was a big thing at that time and that was not big [the drugs], but Thorazine was given all over the place and he was in that awful Camarillo. I was so glad to see that closed down. It was horrible. My husband was dying at that time, so there was nothing I could do until that [happened].

So then I got him out of there and then he went to a County Hospital which was smaller and much better. Then they started to change the meds in the 80's, because NAMI got busy and we advocated nationally for more money [and] for research, because one man was doing research on schizophrenia at NIMH in 1981, [only] one psychiatrist, one man; and so that was our first national advocacy alert, to write to your congressman. We had several states. We had enough states for each to reach their Congress people to say that we want more money for research. And we did that every year and every year we got more money, until eight years ago, and then it kind of maintained; we haven't gotten any additional funding, but at least it maintained what we had, we didn't lose any.

So that has a lot to do with the ability to have the med – Clozaril [clozapine] is the one that's the best to date. My son is on Clozaril and that seems to be generally what has helped most, at the right level, without bad side effects. And, his psychiatrist, who is now at UC Irvine, he's in charge of the psychiatrists and research there. When my son was with high cholesterol, the same as me [she

laughs], and we were both on the same drugs, which I did not like because it made me feel bad! And so he said, “Try niacin.” He’s a psychopharmacologist too, and I’m on that [medication] and so is my son and my cholesterol has gone down. Of course, I usually am on a diet. I keep my diet, I’m practically a vegan.

My daughter is a vegan and it [her brother’s illness] has affected her life. Siblings are an important part – it has impacted her life. She was younger and she had terrible relationships; I mean, I never liked the guys she got [involved with], and she realizes that now, that they were very wrong for her. It took her a long time; and she’s an artist, curator, art teacher, and so on, and she started a program to teach women who are at a shelter, [who are] transitioning back to the community – women with mental illness. She founded it herself in Santa Monica 12 years ago and started a program teaching them art at the college. She is a graduate, a fine arts graduate of UCLA, and she taught them, she started to teach them. She put on an exhibit, and their [self-]esteem went up.

AN: Wonderful.

SM: Yes, and she developed it and she’s added all the arts. It’s a multi-arts program now and we’re trying to get funding for that. It’s coincided with Steve Lopez’s [she laughs].

AN: *The Soloist.*

SM: Yes, and it’s amazing. She has seen so many of the clients, and I have met them too. We go shopping in Santa Monica, because the shelter was in Santa Monica and when she sees some of these clients that have been in the class, they come and hug her and say, “You’ve meant so much.” Some of them – their art, she said, was excellent, and they have gone back to Santa Monica Community College to study art.

AN: That’s terrific.

SM: Yeah, so she’s done excellent, and she put on shows and [she laughs]. I tell you, but it has impacted her life. She would be in a different world. She would still be an artist, but she would have a real relationship or marriage, whatever, and be in a normal situation, more normal than she is now. So that’s the impact of mental illness on the family life, because I know it happens with many others, many mothers in the families. They say, “why don’t you get remarried?” [she laughs] Some of [the mothers] who didn’t get remarried had a divorce because they couldn’t – the husband wanted to retire and go on trips, but [they] couldn’t go on a long trip. So that didn’t make sense. Those who just dissolve their relationship with their [mentally ill] family member, okay, they could do it. So it’s different for every individual.

AN: Sure. So those are all my questions about the MHSA and-

X. In Our Own Voice and its Impact; Speaking up for Clients and Family Members; Influence of Parents and Others; Closing Comments on NAMI

MM: I had just a couple more questions.

SM: Yeah.

MM: Hi.

SM: Hello, Marcia [she laughs].

MM: We've talked a lot about In Our Own Voice, which is such a -- I mean, it sounds like such a wonderful program, it's made such an effect on changing people's perceptions. Could you tell me anything about how that got started?

SM: Yeah, it's a national NAMI program.

MM: Right, I know you said that.

SM: And it was started by our national clients. We have many clients who belong to NAMI. They are either sons or daughters of NAMI families, and they started that and the curriculum was written by one of the education people and the curriculum -- it goes into five --

MM: You mean by a NAMI person who's in education already?

SM: Well, the -- we have a NAMI person who wrote the curriculum for Family to Family. She's in charge. She's a psychologist.

MM: Okay.

SM: And her daughter has mental illness and that is what brought her there. So she originally wrote the curriculum for Family to Family and she's a top level, and if she doesn't personally write the curriculum, she finds the right person to do it and a lot of clients worked on this, who had recovered enough to do it. The first thing -- they have five components. The first thing is "Dark Days." They have to edit this down and rehearse saying it in thirteen minutes. "Dark Days." This is the first thing, when they are trained. Then comes "Acceptance." Then comes "Treatment." Then comes "Coping Skills" and number five is "Success and Hopes For the Future." All of that, in thirteen minutes.

MM: Thirteen minutes?

SM: Yeah. And they do it beautifully. This is what the two day training is about, there are two trainers there, that were trained by [the] National [office]. And they have to write this all down; first they write it down and they have to edit and edit, and they do that the first day; and [for] the second day they rehearse speaking it and get feedback. So that's the basis.

MM: That sounds wonderful.

SM: Then there is also a nationally made video which shows -- it shows people of every race, ethnic background, socio-economic background [and] every gender. There are about six people on this who tell their story in the same way and that takes about 15 minutes and that goes -- When they come on, they introduce themselves and the first thing they are taught to say, is to say what your hobby

is. It's up to them, what they have as a hobby. They like to read, they like to go to the movies, they like to listen to music, whatever it is, the same as everybody else. That's the first thing they say, "my name is blah, blah, blah, and my hobby is..." And then they just [say] a little bit about NAMI, "I got involved in NAMI..." very short, and then they introduce the co-presenter. There are two presenters each time and the co-presenter says the same thing. Then they play the video through and then they go into their total presentation after the video. They each give their total talk. After that, depending on the place, they do it within the hour, with sometimes 10 to 15 minutes left for questions and answers, or if there is time afterward, they stay as long as [they can], in some programs there is time, to answer questions.

MM: That's great.

SM: And they have handouts, brochures and the evaluation forms, which I get after each one and read through, and the evaluations everywhere are very good. Dr. Southard has them doing this. Every month he has Orientation for new employees and that includes everyone from maintenance people to the head people, to professionals, everybody, and there could be clients who have just been hired, family members [that] just [got] hired through MHSA, everybody is there. Everybody who is employed has to go to this meeting and it's usually on Monday and Tuesday mornings. They have various pieces and this is –

MM: It changes your whole perspective.

SM: This is given an hour and he has this at every one and it is really tremendous. And the next – they are doing it at churches. In fact, there was one in Azusa, where he was so impressed that he wanted a family member to be on his committee that was interviewing their nurses, something for nursing staff. For nurses, it's been wonderful. They say, "I only see them when they are sick, but when I see them when they are well, my goodness, it dispels all of my myths." Yes, that's what the nurses have said.

The USC nurses, they have gone to all of their – Her name is Ms. Block, B-L-O-C-K, and they have gone to all of the nurses' graduations in December and May. They just went back this past week. I didn't get their evaluations yet and their nurses are just amazed because, like I say, they only see them when they are sick and they are amazed, and so that changes their attitudes. It's just fascinating and I get the stack, and of course everybody doesn't always hand one in, but they all say that it was fine. Some of them give [when asked], "What changes should be made?" They said, "They wouldn't change a thing." Or "Would like more", to hear from more people. That's the biggest thing. [she laughs] Time is the – If you people give us more time, we will give you more people.

MM: Can you tell us a little bit about, you are still involved, you've been involved with NAMI from the very beginning and now you are on the System Leadership Team. What kind of a role do you play in these groups? Is it mostly speaking from your own experience, do you see yourself as representing other family members?

SM: Oh yeah, I represent LA NAMI, LA County.

MM: So you gather input from other people, or tell me how you – ?

SM: No. It's part of the Los Angeles County Coordinating Council and we meet monthly and we get input from all of our affiliates. We meet monthly with all of the affiliate leaders. There are 10 or 12, they vary. And we hear the input, and whatever comes up there, I know about, and so I bring that up to make a point. I speak up for that. I speak up for issues that involve everybody. I'm not just tied down to what's bothering us [NAMI], but if I see an overall issue, like the business of educating and so on. But I can speak up for all the clients, because they are all similar to the ones that we know in our families and hear about, because we've had family members who have their clients in Twin Towers and they've been all over the place.

I have one now, she's a friend whose sister made her way up to – she lived here and was treated at the Hollywood Clinic on and off; [she] suddenly drove off – There was a man living with her and he died, and left her some money. She drove up to Santa Clara, in that county someplace, and busted the car and the police didn't – She drove into some place and busted the car and somehow they didn't take her to jail. They took her to a hospital and the family had to get up there to the hospital, and they wanted [to take her home] – but she refused to go [back] with them. There are two sisters, one here and one in Bakersfield, who wanted to take her home, but she refused to go. She's 50 years old, they couldn't pick her up and take her [she laughs]; and meanwhile she stayed there and then she somehow got to another county and my friend got called again. She was in another hospital, but at that hospital they had a conservatorship hearing, in conjunction with LA, and she was willing to be the conservator. But she said they are going to have to bring her down; she said, "We can't take her down in the car, she won't get into the car with me to come home. We need a police car to take her down here [she laughs]." She was very funny.

Anyway, I don't know how or whether she got her down here, but she did get the conservatorship and now she said she has to be in an IMD. She has to be under control until she goes off of her meds, because she goes wild. She has an apartment here and she gave her key to a man from off the street. I mean she was just out of it, and they were hoping to get her back to Bakersfield with her older sister, who says that it is nice and open there and she said that she grew up there. It's a small town outside, with lots of open field where she can't do any harm, but she won't go. I mean, all of these problems crop up all the time – The traveling clients that travel all over the states. I don't know how they do it. She had some money that he gave her, or left her, I don't know. They don't know how much he had left her or what she did with it, but she traveled all around the state [she laughs], Santa Cruz, to Santa Clara, San Jose.

MM: Quite a story.

SM: I tell you, but one thing I wanted to bring up again was when you asked, "Who had influenced my thinking and all?" And I had just given you the outside people. I wanted to mention my parents.

MM: Oh, yes.

SM: My parents both came over here as immigrants when they were very young. They went to school here and everything, and they, of course, spoke English and went to school here and everything. But they were very good people, good honest citizens who revered the country, and were very happy with the life they had here and although my mother was only 3 and my father was, I think, about 8 when they came over, and they both finished high school. My father went to work with his father and brother, they started a business and my mother, whose mother had come over with her mother – my grandmother was a widow, they came over and she was left with a cousin. The immigrants would gather in New York with their families and she was left with a cousin in New York, when her mother, my grandmother, came down to Richmond because she married somebody else and he lived in Richmond. Richmond, Virginia.

I was born in Norfolk, so you see a connection coming up and my husband's, my father's family was in Norfolk and they got together and so they lived in Norfolk. But they were very supportive of everything that we did and supportive and were interested in keeping up and voting and keeping everything going, very good citizens and were very honest and they did not complain, they did not complain about anything. They went through the Depression and everything so that was a great thing, family. My sister has been very good, I have a younger sister, and she over the years has been very good, she has been very supportive of my son and I feel very lucky in my family.

MM: That's great.

SM: Yeah, I found a lot of good support there. Not just in the outsiders, because the outsiders were Don Richardson. And I'm getting the NAMI award next month in San Francisco.

MM: Right.

SM: NAMI is celebrating their 30th year and they are giving me the highest honor award.

MM: Sounds very well deserved.

SM: And the banquet is going to be a real fun thing and Dr. House of *House*, he's going to be the master of ceremonies, so it's really going to be fun.

AN: Oh, that would be great.

MM: It should be terrific.

SM: Yeah.

AN: Hugh Laurie.

SM: Yeah, right, yeah, and I think some of the other people, celebrities and media people who were honored in the past, will be there. It's going to be a big deal.

AN: When is this?

SM: It's July 8th, a Thursday night, July 8th or 9th. It's a Thursday night, July 8th or 9th.

MM: That's wonderful.

SM: At the San Francisco Hilton.

MM: Good for you.

SM: Yeah, so I'm looking forward to that.

MM: So I've got one more question.

SM: Sure.

MM: I don't know if you have a comment on this or not, but on the NAMI website, they recently did a report card on all the states and I noticed that California only got a "C," and some states got better grades.

SM: Oh, I know about that very much. They go by the entire state and you know our report on the Proposition 63 was not in yet.

MM: Oh, okay, so it's a little behind the time.

SM: Yeah, it's based on mostly the regular funding and programming, because when the question – when the surveys were made, it was 2 years ago and that was before.

AN: Yeah, a lot of things hadn't gotten started, the FSPs were just starting.

SM: Yeah and they didn't have the outcomes yet, so I think that next time they do it – My supervisor there on Stigma Busters is Bob Corolla who does this, who writes this up, and sees all the reports and I told him about that, so he's watching for that and he's been very supportive, because he himself is a consumer. It's interesting that the staff people at NAMI, and there are about 80, I would say, about 50, at least 50, are clients who have recovered and they have flexible hours and if they have to go to see a doctor, it's okay. It's absolutely fine, and if they want to work at home, it's okay. If they are not feeling well, of course. And they have very good coverage and very good benefits and they are very dedicated, obviously, and if they are – many have a family member who work there too, that's why so much good stuff comes out of there.

MM: Right.

SM: Because they themselves know what it's all about.

MM: That's pretty amazing, though. Okay.

SM: And it's amazing to me. We have monthly meetings of all staff and those of us in the field, and there are more and more in the field that take care of different sections of the country and that's where the reports come in and we're on the

phone call. The executive director who himself used to be on staff as a staff person reported that we are in good condition, financially.

MM: Oh, that's wonderful.

SM: The place has been run so well that the people who give donations are still, they have no problem giving. The big companies that rate them, they are highly rated. I forget the names of the companies, but they are still coming in, there is no problem.

MM: That's great, that's unusual [she laughs].

SM: Yeah, I know, that's why I'm mentioning it. I'm very proud of that.

MM: And so most of the funding actually comes from company grants? Or from?

SM: Well from grants and from donations, donations from the membership, of course, is like 35 dollars, but membership is growing. Our [fundraising] Walks have brought in – our Walks have grown and grown and are growing every year to be the biggest Walk of all.

MM: That's exciting.

SM: And they bring in the money, they brought in a lot of good money and that goes for local, and we share it with National, our Walk here, and we send some to the State, so at the National level, they also help; it comes down through the states to the local and overall, it's been a great experience. Yeah, I'm very proud of them, it takes a lot of doing these days.

MM: No, it is; it's very hard to build a volunteer organization with this kind of strength.

SM: Well, we had a good start up. We had for a few years an executive director who had, thank God he had to go, because we had to say to the Board – the Board finally fired him because he was firing people and hiring his friends and not caring. They got rid of him and that's when Mike Fitzpatrick came in and he's turned it completely around. Fortunately that happened several years ago, so we had time to get this in shape.

MM: Well thank you so much for coming back and so early.

SM: Well that's okay, it's my pleasure.

MM: It's been great talking to you.

END OF INTERVIEW