

Subject: Judi Chamberlin

Location: Arlington, MA

Date: November 7, 2002

Interviewer: Darby Penney

DP: This is Darby Penney. I'm interviewing Judi Chamberlin at her home in Arlington, Massachusetts on November 7th, 2002. Judi, can you tell me where and when you were born?

JC: I was born in New York City, October 30th, 1944.

DP: And where in New York City?

JC: I was born in Manhattan. I was raised in Brooklyn.

DP: What kind of family life did you have?

JC: I was an only child. My parents were very loving. We were somewhere between working class and middle class.

DP: What kind of occupations did they have ?

JC: My dad was a factory worker when I was kid, although later he got out of that and got into more white collar things, and my mother worked as a school secretary.

DP: And where did you go to school?

JC: In Brooklyn. I went to public school, high school and, never really...I don't have a college degree. I sort of dabbled and I got a little bit of college education but not much.

DP: So, what was your first encounter with the mental health system?

JC: I was 21 years old and I was married and I had a miscarriage and I got incredibly depressed and, you know, just, wasn't getting out of bed. Wasn't functioning. Just crying and everything. And my obstetrician— I had a very good relationship with him— got very concerned about me and he said that he thought I should see a psychiatrist. So he referred me to a psychiatrist and I didn't know (pause) anything about the guy, just that I'd been referred to him by somebody I thought a lot of...So, I

went to see him. I told him...by that time I guess it was maybe oh, a month or so after the miscarriage, maybe a little longer. I'm not sure exactly. And I started telling him, you know, what's going on and that I just was miserable and crying all the time and didn't feel like doing anything. I thought about killing myself and...and I guess we hadn't gotten about ten minutes into that interview when he opened up his drawer and he went to all the little pill samples and handed me some pills. He said take these. These will make you feel better. And what they were — I didn't realize how bizarre this was until much later when I learned something about psychiatric drugs —were Thorazine and Stelazine. So, those were the first psychiatric drugs I ever went on.

DP: And did he give you a diagnosis at that point?

JC: No, he just said I was depressed and that this would help me. I used to go see him...I think three times a week I would go see him..., and he would say, "Are you taking the pills?" And I would say, "Yes." And he would say, "Are you feeling better?" And I would say, "No." And we would talk, and I was just totally non-functional.

DP: And how did those pills make you feel?

JC: Just lethargic, but I felt lethargic any way. I didn't really notice anything.

DP: And how long did that go on?

JC: That probably went on for two months and he finally said, "You're really not getting any better. I think you should be in a hospital." So I figured okay, you know, he's the expert., I don't want to live like this. So he suggested I go to Mt. Sinai Hospital in Manhattan. So I went there...I guess I went to the emergency room. I can't remember. Probably. (Pause) And I told them my story and told them my doctor thinks I should be here. And they admitted me and I had no idea what to expect— what do I know about mental hospitals? All I know is from movies and books and stuff like that and Mt. Sinai was a very physically pleasant place. It was modern, light. It was airy. It wasn't like one's image. (pause) But right away there were a couple of things I found very weird. One was that they immediately decided that I should be on different drugs, which just struck me as, you know, they don't know me yet. They don't know anything about me. And they put me on Mellaril.

DP: And you were still on....

JC: No, they took me off the Thorazine and put me on...Mellaril and Elavil.

DP: And they did this abruptly?

JC: Yes, yes.

DP: And did you have kind of withdrawal effects?

JC: No. No. I just thought it was odd, you know. And other thing that struck me as odd was they said, "One of our residents will see you for therapy twice a week for thirty minutes." And I said, "Well, I've been going three times a week for an hour and I'm here because I need more. So that doesn't make any sense." They said, "Well, that's the way it is." So those two things, both of them didn't make any sense. And I'm thinking, this doesn't make sense and I'm thinking, "Well, they must know what they're doing." I kind of believed that they must know what they're doing.

DP: And you signed yourself in voluntarily?

JC: Signed myself in voluntarily.

DP: And where was your husband in this...

JC: He was very unsympathetic. He was very, you know, kind of "Pull yourself together." And...so I was there for two and a half weeks which was, the amount of insurance I had. Like I said, it was not horrible....But it was odd.

DP: So, what kinds of things would go on in the ward on a daily basis?

JC: Well, the one thing that was scary was, there were some patients who were getting ETC. We would see them leave...you know, they wouldn't be at breakfast and then we'd see them come back about, you know, before lunch and they'd be all confused and some times you'd have to tell them where they were and stuff like that. And that was like oh, my God, you know. I don't want that (laugh).

DP: Did anybody either offer you that or threaten you with that?

JC: Later on.

DP: But not at Mt. Sinai?

JC: Not at Mt. Sinai. So that was one thing. The other thing was...it was like being in day camp. You know, now we're going to go to the gym. Now we're going to do arts and crafts. Now we're going to...ah huh...and you didn't get to go outside very much. When you got to go outside it was in an escorted group. We used to literally go to a playground. It was just like being in day camp. (laugh).

DP: So besides finding this weird, was there anything about it that you felt helpful?

JC: Not really. Except it was, it was, it was sort of comforting because it was like, okay, now I'm sort of legitimately lying in bed all day, I can just legitimately do these really stupid things and not have to worry about life.

DP: So you were there for two and a half weeks...

JC: Two and a half weeks. They said I could go home. I thought okay. I must be better. I go home and...wham, it just hits me. Nothing has changed. I can't...I can't...I can't stand this. I can't function. I can't handle this.

DP: And you were still on the Mellaril and the...

JC: Elavil, yeah.

DP: ...that they put you on in the hospital?

JC: Yeah. So it was like, well, I want to go back because...in there it's like (pause)... this vacation from life. So I went back to the emergency room and I said, I can't manage at home. And they said, "We don't have any beds." I don't know if they didn't have any beds or they didn't want me because I didn't have any insurance. I said, "Okay." So I started to leave. They said, "No, you can't leave." I said, "Why?" They said, "Well, you obviously need to be somewhere and we can't take you here, so we're going to send you to Bellevue." I said, "Well, I don't want to go to Bellevue." I said, "I heard terrible things about Bellevue. I know this place, I feel comfortable about being here. But I don't want to go to Bellevue. I want to go home." "Well, you can't go home." So they sent me to Bellevue and I was absolutely terrified and I also kept saying, "Nobody will know where I am." I think I was living with my parents at that point. "Nobody will know where I am."

DP: They didn't let you call anyone?

JC: I think they finally let me make a phone call at some point. But it was, you know, hours and hours later So, they took me to Bellevue. Bellevue was absolutely everything you've ever heard. It's horrible. The first thing they did was take away my glasses. I couldn't see anything. So, I'm walking around like this, you know. I can't see anything. I think by that time it was late at night. There were no beds, so they put me in a cot in the corridor. At one point I get up to try to get a glass of water or go to the bathroom or something and somebody starts yelling at me, "Go back to bed." I can't see anything, so it was like everything was eerie and very, very scary. And it was, the next morning was Easter morning and they said, "Come into the dining room." I guess it was lunch time by that time because... I distinctly remember they said, "Come into the dining room and everybody will get a cupcake with a jelly bean on top." I didn't want the cupcake with the jelly bean on top (laughing). I was afraid to eat the food. I was just afraid...I was terrified and I guess at some point I got to make a phone call because my parents came and they talked to one of the staff

and said, "We've got to get her out of here. How can we get her out of here?" And they said, "The only way to get her out here is to see if you can find some place else that will take her."

DP: So were you actually formally committed?

JC: No, I guess I was on a three day paper or...ten day. I think at that time it was ten day paper. I guess that's what I was on. I don't really know.

DP: But you never saw it or...

JC: No.

DP: ...or they never informed you...

JC: No, no. I just knew I wanted out and I was there for three days 'cause it was a holiday weekend. So they said, "You're not going to be able to do anything until Monday." So, they got me into Gracie Square, which is a private hospital. To this day I don't know how they paid for it, how much money it cost them or all that.

DP: So, their insurance wouldn't cover it?

JC: No.

DP: Oh - you weren't on their insurance.

JC: No, I wasn't on their insurance. And so they had to pay that out of pocket and that was expensive. They weren't rich people or anything. So they got me into Gracie Square. And Gracie Square...as a matter of fact it was very expensive. Gracie Square would only accept me because I was supposedly suicidal. Gracie Square would only accept me if I had a private nurse. So now they not only had to pay for the hospital, they had to pay for two 12-hour shift private nurses. But I was just so relieved to be out of Bellevue and Gracie Square was another place that was...physically it was pleasant. But it was very locked down and it was also very small. So you really felt...I used to call it the gilded cage. You really felt locked up. Mt. Sinai was not a locked unit. What they did to prevent you from leaving was you had to be...you had to be in night clothes all the time. But it was not locked. Some people actually made it down to the lobby (laugh). You can't get too far in your pajamas. So all of a sudden I'm in a place, where, you know, instead of these big rooms, it's small and everything is locked. The elevator would be locked. So, you really got this feeling of being locked up all the time. It was very scary. And they really don't do anything there. I mean, they just keep you there. They do a lot of shock there. It's also a place apparently where a lot of people go with alcohol and drug problems to dry out.

DP: So at this point you were still on the same meds?

JC: I don't remember. I was on something. I don't remember what. It was just that anything is better than being in Bellevue. And I was there, I don't know, two weeks or something along those lines. And I got discharged from there.

DP: And you got discharged with basically them saying you were better?

JC: Oh, I don't remember. You know...I guess at some point, yeah, I guess so 'cause I think at some point they said I didn't need the nurses any more. I remember I had two West Indian nurses. They were night and day opposites. One was this very...you know how some West Indian blacks are like "we are just better than anybody else?" You know, very middle class and she was always telling me about her son at Harvard and all that. And the other was like a real street fighter, you know (laugh). It was really a funny contrast 'cause they both had that West Indian accent but besides from that they were different...plus one was sort of short and plump and the other was tall (laugh, laugh).

DP: So then what happened when you got out of Gracie Square?

JC: So I got out of Gracie Square. I guess at that point I started living at my parents 'cause my husband and I were just totally not communicative. I was living with my parents. I was...I was just totally miserable. I just felt there's no way out of this. I'm just miserable all the time. I don't want to live. They didn't know what to do for me. I guess I was still seeing the therapist who was very ineffectual and he kept suggesting different places that I should go to. I remember, I was interviewed by one psychiatrist who wanted to send me to Day Top Village for some reason 'cause that was his place, you know. I said that's...I mean, I might have been out of my mind, but I wasn't that out of my mind.

DP: But Day Top Village is a drug treatment clinic, right?

JC: Yeah, yeah.

DP: And that wasn't your issue?

JC: No, no. Well, I was taking a lot of sleeping pills. The same therapist suggested I should go to Hillside Hospital, and I interviewed and it was like, you know, trying to get into a good private college or something. And they showed me around. And these are the grounds. See how nice and open it is and you're not locked up and there's all these phones so you can make phone calls and, you know, it sounded really nice. So I get in. They admitted me and said "We're admitting you on such and such date. Here's what you should bring with you and don't bring a whole lot of stuff with

you basically. “ You know, don’t bring a radio. Don’t bring this. Don’t bring that. Basically, just bring your clothes. So, I get there and they admitted me to one of the cottages and then they start telling me there’s all these rules which they hadn’t told me about before. Because one of the things I had told them was that I’d been in this lock up and it was terrifying. I can’t stand the feeling of being locked up, and they had showed me that it was all open. Okay, the rules are, until you get off this level or whatever they called it, you can’t go anyplace unescorted. You can’t make phone calls until we decide you’re ready and you can’t have visitors until we decide you’re ready. So, I said, this is bait and switch here (laugh, laugh, laugh). You know, I made very clear when I was being admitted that I have certain needs, and, and one of them is this need not to feel locked up and confined and now you’re telling me that even though I’m not physically locked up, I basically am. And I think I sneaked in a phone call, you know, because there were these phone booths all over the place and I sneaked in a phone call to my parents. I said this is horrible. It’s not at all like they promised...and I just said I want to leave. I want to be discharged. This is not what you told me to expect.

And there was this other patient, who I became very friendly with, who had a room across the hall. He was a veteran. He had just been admitted for his, you know, multiple time and he had brought a radio and a tape player. What did we have in those days? (Laughing) I used to go to his room and...we used to listen to music. And we used to talk and he kind of introduced me to the ropes. You know, it’s very helpful to have some orientation, what to expect and all that. It was a totally innocent, non-sexual relationship that the staff got very freaked out about, because I would lie on his bed to listen to music and so they got all freaked out about it. And there was no hint of, any kind of sexual stuff going on, but they thought I was weird and I thought it was great to have somebody to talk to and listen to music. So, I’m on this campaign, I really want...I want to leave. I can’t stand it here. You told me all these lies and they’re telling me I can’t leave. I had this roommate who was...I was 21 years old, she was probably about 45, and we just had nothing in common. I said I wanted a different roommate and...never go into a hospital in July or August, ‘cause you get all these brand new interns and residents who know nothing. So I had this...I was assigned to this therapist, this baby therapist and talk about two people who just didn’t click. So I wanted a different roommate and a different therapist. And they, of course, interpreted that as, as some sort of emotional thing instead of “I don’t like my roommate. I don’t like my therapist.” So, of course, I couldn’t get a new roommate. I couldn’t get a new therapist and I want to leave and they’re telling me I can’t leave. And then everybody is talking about there’s a picnic coming up and planning for the picnic. Oh, no, you can’t go on the picnic because you’re new. So, I just got really furious and I’m trying to be rational about it and saying...you know, telling them, “Look I don’t like it here. You told me a lot of things that weren’t true,” and trying to be very sensible about it. And they’re just throwing up all these roadblocks. So when they told me I couldn’t go on the picnic, I just went berserk and I picked up a little table lamp...like a little goose neck lamp and I was trying to smash a window with it because I was just so furious. I said, “Look, I’ve tried to talk to you people for days

now and nobody's listening to me." That, of course, gets their attention. And I was dragged down the hall by a bunch of goons and they wanted to give me a tetanus shot 'cause I'd cut my finger on the glass. I said I didn't need a tetanus shot and they said yes you do and they gave me a tetanus shot against my will. And I guess finally somewhere in all that they decided, you know, they were going to get (laughing while speaking) rid of me. They didn't need me there.

DP: You were more trouble than you were...

JC: I was more trouble than I was worth. So, I think I was there all together about a week.

DP: And then after you were released from...

JC: Released from there, you know, this was like...I mean, I was just on this merry-go-round. I couldn't get off it. I ended up back in Gracie Square for probably another week or so. I remember, I made an ineffectual suicidal gesture and ended up back in Gracie Square. As soon as I got in there, it was like "Oh, no, what have I done? I certainly don't want to be back here." So, I was there for another week and then I was home again. And then I ended up in Montefiore in the Bronx and that was probably...of all my hospitalizations, that was the best one.

DP: Really?

JC: Yeah.

DP: Why?

JC: Good people. Nice human relationships. The other thing that happened in Hillside that made everything so bizarre was they told me they wanted to evaluate me without medication. So they took me off all my medication without telling me I was going to have withdrawal symptoms. So that was the other thing that this guy Jerry, this friend of mine, had said...I said to him, "I don't understand why I feel so weird. I'm hot and I'm cold and I feel like my skin is jumping." And he said, "Oh, yeah. You're having withdrawal symptoms," which would have been a helpful thing if somebody had told me, which would have put it in context. You know, until then I thought I was losing my mind. So when I got to Montefiore, I wasn't on any medication. Actually I felt better not being on any medication. They kept me off medication. So that was good.

DP: Did you find that you bonded with other patients?

JC: Yeah. Everywhere I went there were always other patients that were helpful in one way or other like this guy, Jerry, who told me I was having withdrawal symptoms. A

couple of people in Gracie Square, I remember I hung out with. So I was in Montefiore and...like I said, that was going pretty well. I was beginning to feel like my life had...stopped spinning and, I was getting some sense of where things were going and then disaster struck. Disaster struck because one of the other patients went out on a weekend pass and killed himself. So, the first thing we knew of it was Monday morning and we got called together for the meeting and (pause) there were sort of rumors going around or the...you know, the air was crackling with something. So the staff sort of marched in all together, which was very unusual. They sat down and the head psychiatrist or whatever said...I guess they told us what had happened and they said, "Everybody is very upset." Didn't ask us how we felt. They said, "Everybody is very upset. And everybody feels very insecure because of this, because this is supposed to be a safe place and now everybody is feeling very insecure." You know, all of this was being announced to us. We were being told how we felt. "And, therefore, the community has decided, all of us have decided, the community has decided that, in order to make everyone feel safe, we're going to keep the doors locked."

DP: And did the community say, hey, we didn't...

JC: Well, I certainly said, "Hey, I didn't decide that." I said, "I've been in lock ups and I can't stand them and they make me feel really unsafe and that's not what I've decided." I mean I really spoke up. And that, of course, carried about as much weight as a two year old saying no, I won't go to bed (laugh). But it was this...the way it was announced was so bizarre. So I said, "You know, if you do this, I'm going to lose it. I just...it's going to make me feel really horrible." And I said, "Since you've changed the rules without consulting anybody, I don't feel like I have to obey any rules." So, I didn't want to...I didn't get dressed in the morning. You're supposed to be dressed to go into the dining room. I went with my pajamas on. So they said I couldn't be in the dining room, so I took my food and ate it in my room. And they said I couldn't eat in my room. So they were going to starve me into submission. So I was having visitors bring me food. Then they said the visitors couldn't bring me food. So things really went very rapidly down hill and I used to stand by the locked door and rattle on it and say, "Let me out. Let me out."

DP: And were you committed or were you a voluntary patient?

JC: No, I was a voluntary patient. So I guess they didn't want another suicide, and they began getting rid of everybody. People were either getting discharged or sent to other places. So that's when they told me I was getting committed. And within about four or five days they must have gotten rid of ten people. Anybody who they thought might reflect badly on them, I guess. So, they told me I was being committed to Rockland. I was furious. I couldn't believe that they could do that. So I started making phone calls. I remember I called the New York Civil Liberties Union and Legal Aid Society and I got absolutely nowhere. One of them...I can't remember

which one said...the person I talked to said, "Well, if that's where they think you should be then that's where you belong." I thought, "How can this be happening?" How come nobody wants to help me? Nobody sees this as wrong. I mean, it just struck me as so incredibly wrong that you could just be sent away like that. At that point it was 60 days...60 days on certificate. And it just struck me, this is wrong, this should not be allowed to happen.

DP: And this was...of course, I think this was before they had Mental Hygiene Legal Services or automatic attorney representation?

JC: Well, I think they had Mental Hygiene Legal Services or something like it because, what happened was..."Okay, I'm going to be sent to Rockland." I said, "How am I going to get there?" They said, "We're sending you in an ambulance." Actually what happened is they took in an ambulance down to Bellevue, which was a collection point, and then they took us in this thing called an ambulance which was actually an old school bus painted white with mesh windows.

DP: And how much notice did you get that this was going to happen?

JC: Well, it was probably a couple of days...two or three days. I don't remember exactly. Not longer than that. So we're in this bus which was called an ambulance and this lady in a white uniform who's called a transfer agent...like we were a bunch of packages (laughing and speaking) you know, like UPS or something. And I'm looking at her and I'm looking at this bus called an ambulance (laughing) and I'm like, you know, this is scary. I'm looking at the cars going by on the highway and I'm saying to myself, "Does anybody realize that people are being transported against their will here? Does anyone realize? Does anyone care?" And the other thing that I still remember and I will never forget this as long as I live...there was a paper bag on the seat behind me that somebody had dropped off to be taken up there for a relative I guess. And on it was written "For Leroy Lemons, age 7." And I'm thinking to myself what did poor little Leroy Lemons do?"

TAPE 1, SIDE 2

JC: I don't remember names and stuff like that. I'm always fumbling for people's names. But I will never forget that as long as I live.

DP: So how did you feel on the ride up there?

JC: Oh, God, it was like, is there anyway I can get out of here somehow? Can I, you know, can I jump? Sneak away? Can I...anything.

DP: And how were the other people on the bus acting?

JC: I don't remember. I don't remember the other people on the bus. I just remember the transfer agent and the bag with Leroy Lemon's name on it. That's the only thing I remember. And those things I remember distinctly. I don't remember how many other people were on the bus, what they looked like, anything. I know there were other people.

DP: So what happened when you got to Rockland (State Hospital)?

JC: Okay. Once I got to Rockland...Rockland was your nightmare, you know. The old...the barred windows and the big doors that opened with the skeleton keys and the...well, you know, yeah. And two attendants took me into a bathroom and they had me strip and they inspected my body for scars and identifying markings including, you know, the bend over and spread your cheeks bit. And then they said I could get dressed and then they handed me a piece of paper about the Mental Hygiene Legal Services or whatever it was called at the time. And it was like (laugh, laugh) the juxtaposition was sort of...these are your rights. Nobody cares (laughing). And then they brought me into a ward and it was one of these big rooms with the wooden benches. TV blaring on one end. Radio blaring on the other end. And they took all my clothes and they gave me some old shapeless dress 'cause they said my clothes had to be marked for identification. When they came back they had written my name with laundry pen on all my clothes, which ruined them. Even though they had nametags on them. I had name tags put on them for Hillside. So next to the name tag they inked in my name. But I didn't see them again for a week, you know. A week or more. All I had to wear were these flour sack dresses. You know, size 92.

DP: So were the wards segregated ...

JC: Segregated by sex, yup.

DP: Do you know how many women were on the ward?

JC: Oh, maybe about 30, something like that, ranging from late adolescence to probably women in their fifties. And it was awful. It was just horrible. So I get into this day room and I sit down on one of these wooden benches and I put my knees up. Put my head down on my knees. You know, the classic position with your arms wrapped around you...and I started to cry. I was like, you know, where am I? Why am I here and how am I ever going to get out here and can I just get lost in here and never get found again, you know? And so I sat down on this bench and started to cry. And this other patient walked up to me and she sat down on the bench and leaned over and she whispered to me. She said, "Don't do that. They'll think you're depressed." And I was like okay, here's a useful piece of information. Take what you can get, you know. So after that I used to cry under the covers at night. And it was just nightmarish. They used to get us up at 5:30 in the morning. We slept in these little cells, locked. And they would open the doors and...

DP: So you had a single room?

JC: A single room, yeah. Like a cell. Yeah. With a window that had a big screen on it. You couldn't open it or anything. And so they'd get us up at 5:30 in the morning. You had to get dressed and make your bed with the bedspread. Then they would lock the door and you wouldn't see the room again until at night when you had to take the bedspread off.

DP: Okay.

JC: Yes. So you'd make the bed with the bedspread. Then you would go into the day room before six o'clock and you would sit there until eight o'clock when it was time for breakfast.

DP: So did people talk to each other?

JC: Some. There were a couple of women who I found congenial and talked to. There were these teenage girls who were like hyper. They used to dance to the radio all the time. There were people at all different levels of "with-it-ness" or "not with-it-ness."

DP: Did you find that other people felt as outraged as you did about it - like, "how can they have the nerve to do this to me?"

JC: I didn't really talk about it. I mean, people talked a lot about wanting to go home. But I used to have these fantasies...I used to have a fantasy that somehow we all had a revolution or something, and we'd march everybody out of the hospital and make sure nobody was inside and then we'd burn the buildings down and we'd dance around.

DP: So you got in the day room at six o'clock and you had to sit there until eight o'clock?

JC: 'Till eight. Yeah. Some of the rules were just so cruel. They could have left us sleep another hour and a half. The other thing that they did that was really, really cruel was during visiting, which was twice a week. And my parents always came twice a week. And when it was visiting hours, there was this huge bathroom called The Section. And it had these wooden benches in it and showers and toilets...toilets without any stalls or seats.

DP: And why was it called The Section?

JC: I have no idea. But when it was visiting hours, everybody had to go into The Section. And when your visitor came, they would come and call your name and you would go into the day room and sit with your visitors. If you didn't have any visitors, you had

to sit in the bathroom for three hours. That just struck me as so cruel. It's like rubbing your nose in it.

DP: That's bizarre.

JC: Yeah.

DP: And they think we're crazy?

JC: (Laughing)

DP: So, how did your parents feel about what was going on?

JC: They didn't want me there. They wanted to get me out. So, those were two things that...and the thing about the bedspreads....struck me as really weird. And we used to clean. You know, we'd run the floor polisher and dust. I guess that was actually in the ward I was in later where we used to do all the cleaning.

DP: So this must have been before they banned involuntary patient labor.

JC: Yeah, but...but you did it because it was something to do. We used to go into the kitchen and wash dishes. They had these big, industrial dishwashers. You put these dishes in these racks and put them in this machine and we used to do that. We used to polish the floors. We used to dust. There was just so little to do. I mean, I was just trying to get through the day, you know. There was occasional activities...very little. There was something called group therapy which consisted of listening to somebody sort of lecture us (laugh). I actually ended up having a therapist, because somebody took an interest in me and I had this very nice therapist who used to send for me every now and then and talk. But...there was like nothing to do. It was like these endless, endless, endless days and the food was unbelievably horrible. I have talked, to lots and lots of people who have been locked up and everybody says the foods horrible. But nobody had what we had. Because...people say, oh, you know, they used to give us meatloaf, you know, it's really sloppy and full of filler or they used to give us things that were just sort of tasteless. We used to get things that were unidentifiable. Absolutely unidentifiable. It was like this plate of brown glue with threads floating in it. I mean, it was not identifiable as any item of food and I just didn't eat it. They used to have bread and margarine and I used to just go and eat a whole lot of bread and margarine because the food was absolutely uneatable. It was just gruesome.

DP: You said you were there for...

JC: I was there for two months. So I was on that ward. I got transferred to another ward. I think I was on three wards all together. Maybe only two. But I got transferred to this ward that was supposed to be for "well behaved" patients and it was...it certainly

was a lot easier than that ward. There were two adjoining wards, and I had a good friend in the other ward and her nurse, was the one who used to make them do all that cleaning. We didn't do as much cleaning, but I used to finish my cleaning and go over and help her with her cleaning. Just to be with her.

DP: So were you allowed outdoors?

JC: Ah, a little bit.

DP: But escorted?

JC: Yeah. I think there were these courtyards.

DP: Were you on meds, any medication?

JC: Yeah, that's the other thing. I had been off medicine. They took me off meds at Montefiore, before all this hell broke loose...one of the other things they decided was I should go back on medication and I said, "I don't want to go back on medication. I took it. I feel that it didn't help me any. I feel better without it." "No, no, you have to go back on medication." I used to spit it out. At Rockland...the first thing I decided when I got in there was, any rule they set, I'm going to obey it. My only goal is to get out of here. Any time anybody says don't put your toe over this line, my toe will stay on this side of the line. I'm not playing around with these people. And they used to literally open our mouths and look inside. As a matter of fact, the first couple of times they gave me liquid Thorazine, undiluted liquid Thorazine which burns. So that was sort of like, you know, if you don't take your pills.... (laughing). So I didn't try spitting them out there. So I was back on Thorazine.

DP: And how did that make you feel?

JC: Miserable. You know, slow. I was gaining all this weight from the drugs and from living on bread and margarine and I was big, slow and...you know, your mouth was dry all the time. The first ward was locked and the water fountain was outside and you only got water once in a while. I used to sit and think about water. So I got into this other ward where you could sort of run your own life there. You could go in your room. You could have books. It was much less regimented, but it was like, you know, serving out my time 'cause I figured at the end of 60 days if they have anything on me, they're going to keep me longer there. And if I really don't do anything, they can't keep me, and that's what happened. When 60 days was about to run out, they gave me voluntary papers to sign and I said, "If I sign these, does that mean I can sign a three day letter?" And they said yes. I signed the papers and I wrote a three day letter.

DP: So what happened when you got out?

JC: Ah, I just sort of was trying to put my life back together. I just knew I didn't ever want to go back so, I figured whatever happens, however miserable my life is, it can't be more miserable than this. So stay away from the mental health system. I actually got hooked up with a very good therapist. You know, just like the first therapist had been such a creep. I knew I didn't want to see a psychiatrist 'cause I didn't want medicine. I didn't want anyone to commit me. Oh, that's another story I left out. When I was being discharged from Bellevue, I was interviewed by a psychiatrist and I said I was leaving and I'm very glad I'm leaving. I don't want to be here. "Oh, this is a very good hospital and we can do very good things for you here." I said, "What can you do for me?" And she said, "Oh, I can give you ECT." So I said, "Well thank God I'm leaving (short laugh)."

DP: When you were at Rockland, did you see any...were they doing ECT there and did you see other people...

JC: I didn't see people getting ECT there. One time this friend of mine...I can't remember her name now...she and I went looking for the arts and crafts room or something and we got lost and we found this geriatric ward. And I thought there were old people on my ward. These were like these little dried up old ladies who were like ghosts. Oh God, it scared the hell out us. (laugh).

DP: And were they all physically infirm, were they were in bed?

JC: Yeah, yeah. They weren't in bed but they were physically infirm. They were really old.

DP: You know, I think at that time they were still doing lobotomies at Rockland. Did you ever run into any...

JC: That may be what we saw. I don't know. I mean, God knows. But that was scary.

DP: So when you got out did you stop taking the drugs?

JC: Well, I started seeing this therapist who was really good, and started weaning myself off the drugs. It was like, just go down a little bit at a time, which I did until I was off them completely. And I started seeing this therapist who was really good. And he was...the first time I went to see him I said, "I don't even know if you want me for a patient because I'm a chronic schizophrenic and I'm never going to get better," and he said, "Who told you that?" And I rattled off all these hospitals and he sent for all my records. He didn't show them to me actually. He read them. And he told me they were basically a bunch of crap and mostly written by residents who liked to use big words and all that. He said, "Who do you want to believe? The resident or somebody who's been in practice for 25 years like me?"

DP: And he wasn't a psychiatrist?

JC: No. He was a psychologist. And he was really good. And he just built my self confidence and self esteem back; at that point, I had none.

DP: So at what point did you go from having a diagnosis of depression to them telling you that you were a chronic schizophrenic?

JC: When I was being committed. People at Montefiore. I kept saying, "Well, what's wrong with me? What's wrong with me? Why are you sending me to this hospital? What's wrong with me? Why can't I go home?" And they said, "You're a chronic schizophrenic."

DP: And how did you react to that?

JC: Well, it's like, you know, a death sentence.

DP: But you believed them?

JC: Um, well, half. I mean, all through this whole thing it was like half of me is saying none of this makes any sense, and half of me is saying what do I know? Until I got to Rockland. At that point it became very clear that I was, making a lot more sense than anybody else.

DP: And that was the last time you were ever...

JC: Ah huh. Yup. I got out in October of '66. The whole thing started in March of '66 and I got out in October of '66 and I've never been in the hospital since (pause) 'cause I knew I don't ever want to go back and one of the ways you don't ever go back is you don't do stupid things like go to an emergency room and say, "I feel like killing myself."

I have to get some more tea. Do you want any more?

DP: Okay.

JC: I'm gradually putting my life back together. Like I said, this therapist was really good. He just said to me, "Don't believe all this diagnosis crap" and...I could just as easily have ended up with somebody else who told me the opposite. So that really helped. And I had a lot of anger, which I felt was very legitimate. I wanted to do something about it. I didn't know what I wanted to do about it. But I wanted to do something about it. You know, this is 20th century America and these things aren't supposed to happen and nobody cares about it and why not? But actually, I didn't tell very many people that this had happened to me because, you know, you wonder how

people are going to react. So, I walked around with that feeling of "I want to do something about it, but I don't know what to do about it" for five years. And that's when I found MPLP...Mental Patient's Liberation Project which had been started by Howie The Harp in April of '71 and I found it, I think, in July or August of '71.

DP: And how did you find it?

JC: Ah, there was a little thing about it in "The Village Voice." One of those little community service announcement things. And I saw it and I looked at it and I thought...just from the name of it, I thought, "This is what I've been looking for. There's other people who feel this way." 'Cause until then I had the idea that I was the only person in the world who thought that way. And as soon as I saw that notice, it was like, "Hey, there are other people in the world who feel this way." I didn't even have to go to meetings to know that.

DP: So what was your first meeting like?

JC: It was great. Every one started out by introducing themselves and saying their names and what hospital they had been in and how long they'd been there. And there were people who had been in the hospital for like ten years, fifteen years. And one guy said his name and how long...what hospital he'd been held in, and then he said "escaped." And everybody applauded. (Laughing) And I was like, "Hey, wow, you know. I'm not crazy." It was really exciting. It was just really like finding something that I needed.

DP: And do you remember how many people...

JC: Maybe 15, 20 people. There was this sense of doing something new and different. I mean, a lot of people had been involved in one way or another in the civil rights movement, the women's movement or whatever. It was like, "Okay, here's something for MY people."

DP: Do you know what prompted Howie to start the Mental Patients Liberation...

JC: Howie...he had started it, but he had already left by the time I joined. I didn't meet Howie until later...maybe six months or a year later. And he had been out to Portland, Oregon and met up with these people called the Insane Liberation Front. And he said we really need something like this in New York City. So he went back to New York and started the Mental Patients Liberation Project. And we didn't realize it, but at the same time that MPLP started in New York, MPLF started in Boston, which was very weird 'cause it's almost exactly the same name, started at the same time...April of '71.

DP: And who started that?

JC: Gil Frost and a woman named Mary Waters who I never met, and another woman named Betty...oh, what the hell's Betty's nameactually Gil Frost left a heart-rending message my answering machine a few months ago and I was in the throes of some other stuff and I never answered it. He was in a nursing home in Kansas City. I feel really guilty about it. It got erased before...I meant to save it and somehow it got erased.

DP: So, what was it like being part of the Mental Patients Liberation Project?

JC: Oh, it was really exciting. It was like, we're challenging this thing that was this horrible force in our lives, and we're going to challenge it and we're going to bring out the truth. We're going to expose it. We wrote up these flyers, and we used to go distribute flyers in front of Bellevue Hospital so that people could take them into the people they were visiting, to take inside to let people know that they're not alone. And we organized. Somehow we got invited to talk at a couple of college classes, I guess. And we got invited to talk on the radio. The first time I went to talk on the radio, we didn't give our own names, and the guy invited us to come back. And we were talking about it afterwards and we said, you know, we have to give our own names. If we're going to stand up for this stuff, we've got to really do it. So we gave our own names. And "One Flew Over the Cuckoo's Nest" was playing Off-Broadway, and we went down and we leafleted the audience to say it's not just, you know, it's not just the things on the stage, this is **real**. And we're trying to recruit members and this woman came up to us and said, "Well, I'm not an ex-patient. Can I join?" And we said no. It was just for ex-patients. And she said, "Well, you don't understand. I'm a patient right now." I said, "Yeah, yeah, you can join." (Laughing)

DP: So is there anybody from that time period who's still an activist...

JC: Ted Chabasinski was at that meeting.

DP: Ah huh.

JC: I don't remember anybody else...But, I guess it was the next year...it was the first conference on Human Rights and Psychiatric Oppression, which was in Detroit, which I didn't get to go to but some other people went.

DP: And who organized that?

JC: Sue Budd. Sue and Dennis Budd were there. I think Leonard Frank was there. I didn't get to meet them until the next year. We got this call from this psychology professor in Detroit whose name was, I think, Tom Hertzberg. And he wanted to organize this conference. Well, he was calling it The Rights of the Mentally Ill, and he was smart enough to realize that he should get in touch with us. And we said we

thought it was a great idea to have a conference but you can't call it The Rights of the Mentally Ill. So somebody in the group, Tony Colletti, the guy's name was, came up with this name Conference on Human Rights and Psychiatric Oppression. And I didn't get to go, but apparently there were 50 people there and it was really exciting and they decided they were going to hold another one the next year in (unclear location) which is the first one I went to. So, it was just the sense of being pioneers and challenging something that had really directly affected people's lives, I'd been in the hospital a few times for a few months but all these people had been locked up for years and years and years. (Short pause) Ah, but the other thing that happened was that this group was riven by factionalism. It kept splitting into these different factions and there were all kinds of accusations and this and that...

DP: And what were some of the issues...?

JC: I don't even remember. I think it was mostly personalities and everybody wanting to be in charge. There were a lot of real macho guys, you know. There wasn't room for more than one of them per group (laugh). I mean at the time they seemed like very big issues, but I don't even remember what divided us up.

DP: So then did the group break apart?

JC: Yeah, we broke apart and we had another group that's called Mental Patients Resistance, and there were three or four different factions.

DP: And was there a common shared philosophy and was it written down?

PHONE RINGS. INTERVIEW INTERRUPTED.

JC: So you were saying, what was the common philosophy?

DP: Yeah.

JC: Yeah, we did write the Patient's Bill of Rights, which was reproduced in my book. And the common themes were opposition to all forms of involuntary commitment and forced treatment. Opposition to drugs. Just the basics, you know: liberation, freedom, equal rights.

DP: So there wasn't at that point a kind of split like a consumer/survivor split...people who liked the system and just wanted it to be nicer?

JC: No, no that was later, when the government got involved (laugh). Yeah, as far as I was concerned, the only reason why anyone would want to join a group would be to oppose involuntary commitment. It really shocked me later on when there were people who wanted to be part of the movement but didn't think it should be opposed

to involuntary commitment. And that never made sense to me. It still doesn't. (Laugh) What else did we use to do besides fight each other...? We had the conference, and then it was knowing that this was happening in other parts of the country and also that it was international, 'cause Don Weitz from Canada was at an early one. And it was only much, much, much, much, much later on that we found it really was international because stuff was going on in Sweden and the Netherlands and Japan and...

DP: Do you think it all started fairly spontaneously and...

JC: I would see it like this mushroom. You know, there was this big thing underground and then it pops up in a whole bunch of different places. Because it happened in 1971, a lot of groups got started, not only different parts of the United States, but different parts of the world.

DP: And most of them hadn't had contact with each other?

JC: Not at all. It just happened. I remember when we first heard about the group in Boston and we drove up to Boston to meet with some of the people. It was so amazing...another group in Boston.

DP: So this is still 1971?

JC: This is 1971, 1972.

DP: And you were still in New York City?

JC: Yup.

DP: And being part of this group was a big part of your activities?

JC: Yeah, but I had a full time job.

TAPE 2, SIDE 1

DP: Where were we?

JC: We were talking about this sense that we're really challenging these really very fundamental things that are really very important in our lives and we really saw it as being part of this whole late sixties/early seventies revolution: civil rights and the women's movement, gay liberation and all that...It just made perfect sense that we needed it, too. But even then, it was really clear that there were a lot of people who considered themselves progressive and left and all that, but just didn't get it. A lot of

people in the women's movement didn't get it. A lot of general left-type people didn't get it.

DP: I think still to this day there are lots of people who are otherwise progressive, who just plain don't get it.

JC: Oh, yeah.

DP: Why do you think that is?

JC: Some times I think it's because they've had personal experiences in their family and they just think. well, this person is really nuts, crazy, whatever and they really can't deal with them. Some times I think it's because they're therapized... I think that's certainly true of the women's movement. There were just so many therapists. There's this wonderful book about the women's movement written by two British psychologists, one of whom is an ex and an activist. It's called *Changing Our Minds*. It's about how the women's movement kind of got hijacked by the therapy movement. About three or four years ago, this British magazine that's published by Mind (which is kind of like the British Mental Health Association but it's much more radical than ours, although the activists there find it pretty conservative) asked me to do an interview with Noam Chomsky. And I was so thrilled, you know, I was going to talk to Noam Chomsky about these issues. He didn't get it at all.

DP: You're kidding me.

JC: Didn't get it at all. It was so disillusioning.

DP: Oh, that is disillusioning, because he's my hero.

JC: Yeah, he didn't get it at all.

DP: Ah, geeze.

JC: I was so disappointed I never wanted to transcribe the tape.

DP: Oh, that's really sad.

JC: Yeah, it was.

DP: You think that once someone explained it to him, he would...

JC: (Over talking) No, I tried. I kept trying.

DP: Oy vey.

JC: Yeah (laugh, laugh).

DP: Oh, man. That really ruins my day.

JC: I'm sorry.

DP: Well, I'll never write him in for president again.

JC: (Laughing) Yeah. I felt the same thing. I figured that someone that bright, with that good a political analysis of things, someone who really sees all kinds of oppression...It's about medicine, he kept saying. It's about illness and...

DP: And that's the thing that I've heard from other progressives who say oh, it's a medical thing.

JC: Ah huh. Yup.

DP: But even still. Even if you believe that it's a medical thing, which I don't, why does that justify the violation of human rights?

JC: Right. If you're walking down the street and a dermatologist looks at you and says, "God, you've got the most terrible case of acne I've ever seen. Come to my office right now," and drags you there by your hair (laugh)...

DP: Well, anyway, so back to New York in the mid-seventies.

JC: I was working full time at this crummy job. And, you know, fitting the activist stuff in wherever I could. And I guess at some point, we had heard about a group in Vancouver, and that they actually had money and they were running all these projects and stuff. And Ted went out there to check it out and he was really impressed. So then I decided to go out and check it out and I ended up staying in Vancouver for a year.

DP: And how did they get money?

JC: They got money from the government which, to us at that point, was just totally unimaginable.

DP: That must have been a first.

JC: Yeah. Well, people in Canada were really amazing. I remember the agency that funded them was...I forget the name of it, but it was roughly equivalent to our anti-poverty type agency. They used to advertise on the radio. They used to say, "Look around your neighborhood. Is there like an old playground that needs fixing up? Get

some of your neighbors together and apply for this money.” It was really much more...our anti-poverty program right away got totally bureaucratic.

DP: Right.

JC: This was really grassroots, and community groups could get together and apply for money and it really worked. So they had started -actually it was a similar story to my story about the psych ward I was on where the guy had committed suicide. There were a bunch of people who were going to this day hospital in Vancouver and one of the rules in the day hospital was you weren't supposed to contact people in the group outside the group. So, one of their number committed suicide and one of the results of that suicide was people circulated this clandestine phone list so they could talk to each other 'cause they were pretty shook up by it. And after a while they realized, my God, we're getting much more support from this phone list than we are from anything in the day hospital. So they organized this public meeting and a bunch of people came and they were saying people needed support. It was less political from the beginning. It was much more about support. People need support and they're not getting it, and here's our experience. What can we do about it and how can we make sure people get support? And somebody who had come to the meeting who wasn't a member of this little core group, said, "Well, I own this house and we could, start having a place where people can hang out in the basement of my house." So, right from the beginning they found themselves running this kind of drop-in center. And then they got...I think they got five hundred or a thousand dollars from the University of British Columbia senior class. That was their first grant and then they applied for a government grant and it just mushroomed.

DP: So, you stayed there a year?

JC: I stayed there a year and what they were doing was interesting. But that's when you began to see this split between the services and the political stuff because I was always seen as being so political and so American and so aggressive. And they didn't limit the membership to ex-patients, and what that worked out to in practice was that the paid jobs mostly went to people who weren't ex-patients. So, it became this two class system kind of thing. And it was much more oriented around services. I mean, they were good services. They were very egalitarian and based on support. Based on people being together and having a place to go and having a sense of belonging and all that.

DP: Was there a philosophical debate then about, you know, the existence of quote mental illness?

JC: I think different people believed different things. I think there's really a cultural difference between Canada and the United States. It's very hard to see when you first go there because, you know, it looks the same. You're talking the same language

more or less...a few little Canadian-isms, but there really is a tremendous cultural divide. And, Canadians are nice. Canadians don't like things to be ruffled up. So it was much more sort of a live-and-let-live thing. Whatever you believe is good. Whatever I believe is good, you know, we're not going to argue about it.

DP: So, why did you decide to leave Vancouver?

JC: Well, I was in the country illegally for one thing (laugh).

DP: Oh.

JC: And also, there were things about that the organization that were really good. There were things about the organization that I didn't like at all. And actually when I went back years later, everything I predicted came true, because it did become a service agency. A good, liberal, moderate service agency, but it did definitely become an agency and still had a lot of the rhetoric about it being member run but it wasn't really. And I saw that right from the start...as soon as most of the paid jobs were in hands of people who weren't ex-patients. This can't be good.

DP: So when you were left Vancouver, you went back to New York?

JC: No, I lived in Bellingham, Washington for a while, and then I moved to Boston. I moved to Boston the end of '75 and got involved with MPLF. I had met the MPLF people a couple of times. They were great. I mean, MPLF was probably the purest, clear, radical group and they had a very good analysis. They wrote this book, "Your Rights As A Mental Patient in Massachusetts." They were doing in-hospital organizing.

DP: How did they get allowed inside?

JC: This actually happened before I got there. They got invited by a volunteer at the old Boston State Hospital, which isn't there any more, to come in to do what was called a current events group. And the current event that people wanted to talk about was their rights. So they're running this rights group inside the hospital for months without the administration really being aware of it, and when the administration became aware of it, they kicked them out. So, the patients on the two units that they worked on organized a petition. Eighty percent of the patients signed the petition and they were invited back, with certain strictures, but nothing that limited what they did really. And that kind of led to the Rogers Case and...

DP: Can you explain what that is?

JC: Yeah. At about the same time that MPLF was running this group in the hospital, Greater Boston Legal Services decided they wanted to do a test case about the

conditions in mental hospitals and they set up shop in Boston State also. And the patients who became the plaintiffs in the suit were all people who were real active in the group. It took a certain amount of courage and there was a lot of retaliation toward the people who got involved in the lawsuit. One guy who lived there for like fifteen years or something—that was the only home he had ever known—was discharged with 24 hours notice and no place to go. You know, stuff like that.

DP: And what was the outcome of the case?

JC: Well, at the time, we thought it was good, but it hasn't turned out that way. The judge said that they could not medicate people against their will except in an emergency, and there was no such thing as a continuing emergency. If they wanted to continue to medicate someone against their will, there had to be a court hearing and what was called a Substituted Judgment Hearing. But what's happened in practice is that it's become total rubber stamps.

DP: So before that case in Massachusetts, people didn't have a right to a hearing or a right to refuse medication?

JC: No, no. And they were doing a lot of forced medication (pause) and also forced seclusion, which was in the suit, but the suit really became focused on the medication issue. So, when I joined, it all that had peaked. But it was just full of a lot of people who had a really clear analysis of what was wrong with the system. And eventually we got involved, I think in '85, we started the Ruby Rogers Center and that came about over a period of several years. We used to get calls all the time. We used to have a group. We used to meet once a week and it was like a business meeting. You know, who's going to do this and who's going to do that. And we used to get calls from people who would come to a meeting or two. They didn't want that. They wanted a place to hang out. And we just began to feel it was an unmet need. But it was very controversial, because it meant taking government funds and it meant kind of toning down the activism and that's very much what happened. I mean, you got so involved in running a group. And a lot of people who come to a group like that are not interested in activism or analysis. They're just interested in feeling better, which is a legitimate thing but, you know, it's a question of whether the drop-in center model is a good one or not. I'm not really sure. On the one hand, I think it's really important to reach out to people who are very enmeshed in the system. On the other hand, how do you begin to move people from just being enmeshed in the system and having this nice comfortable place to go to, to a becoming an activist? To realizing there is more to life than finding your niche in the mental health system. One of the great failures of this movement has always been that we have not reached too many people who are outside, who are no longer enmeshed in the system. Yeah, it's a real problem because I do think it's important to reach out to those folks.

DP: Yeah.

JC: But it's also important to get involved people who are not involved with the mental health system but still feel that having been a patient was a very important part of their lives and they have all this anger about and all these feelings about and want to do something about it. And a lot of those folks are... you know, it's a lot easier to find the folks who are still in the system.

DP: When did you start writing your book, "On Our Own"?

JC: I started writing that when I was living in Bellingham. It was '75 and I just felt there was all this stuff people didn't know about mental health and about that there really were alternatives to putting people in mental hospitals and drugging them. And people who had this experience really had something valuable to say and really couldn't control their own lives. So I just started writing.

DP: Did you get a lot of encouragement from people in the movement?

JC: Oh...

DP: Did people know you were...

JC: No, I don't know if too many people knew I was working on it. I think when it got published a lot of people were sort of like, "How come she wrote the book?" Because I sat down and wrote it (laugh).

DP: So, how long did it take you?

JC: It took me about nine months to actually write it. I mean, I had written parts of it and I really wasn't working on it seriously. I was still working on it until an absolutely fluky thing...you know, one of these where you know somebody who knows somebody who knows somebody. I met this guy who was a writer and had an agent and read what I had written and said, "This was really good. I want to show it to my agent," and that just doesn't happen very often. And then once we got a contract, I sat down and actually worked on it like it was a job.

DP: So how did that change your life once your book was published?

JC: It began to lead to things like speaking engagements. And we were getting more involved in government stuff anyway. I remember when I first moved to Boston, around '76, we got invited to this group that had been set up in Washington called The National Committee on Patient's Rights. And Howie The Harp said, "Hey, wait a minute. You can't have something like that without real patients."

DP: And this was a government group?

JC: No, this was ...I guess it was spearheaded by the Mental Health Association...the National Mental Health Association...

DP: Oh.

JC: But there was some NIMH (National Institute of Mental Health) people involved in it. There were some Mental Health Law Project staff (that was before it was the Bazelon Center). And us. It was starting right around the time I moved to Boston and I went to the MPLF meeting and I said that I'd really like to go to this meeting. And they said, well, why would you even talk to those people, blah, blah, blah. But I have always thought it was important to talk outside your own group. So I started going to those meetings and they were, you know, well...there's a big difference between liberals who want to make the system nice and better....

DP: Yeah.

JC: And people who say, "Wait a minute. There's something fundamentally wrong here."

DP: And that group was primarily the former?

JC: Yeah, yeah. You know, it was very clear who were the ex-patients and who were the other people. But that led to my making a lot of contacts with people and one thing sort of just led to another in a very gradual way. But it's always been very clear to me that if we don't keep focused on fundamentally changing the system and challenging the wrongness of it... And people would say, "Oh, but it's medical." But it's *not* medical. My other doctors don't do that. If it's medical, then that's fine. You know, hang up a shingle and practice medicine. That doesn't bother me any. I'm not one of these "abolish psychiatry" people. I think that's silly, frankly. I just don't want them to have all this power. They want their psychiatrist, fine. Somebody wants to be a patient, that's fine. Like Szasz says, as long as it's a relationship between consenting adults.

DP: So, meanwhile, were the annual conferences continuing?

JC: Yeah, yeah. There were annual conferences. The first one was '73, I think. I hope I got that right. The next one was '74 in Lawrence, Kansas. And that was the first one I went to. I went out on a Greyhound bus with Howie and Ted.

DP: Ah huh.

JC: And we went out about six weeks before to help them organize. That was another culture clash. The Mid-West versus New York.

DP: I bet.

JC: We were like, "Hey, let's get things done," you know, and they were laid back Mid-Westerners. Plus there were a lot of professionals involved, professionals and students. There were some ex-patients. When that conference happened, that's when I met Leonard (Roy Frank) for the first time, and Don Weitz. And, obviously Sue and Dennis (Budd), who I just saw out in Kansas a month or two ago. Wade Hudson who... Leonard and Wade were the ones who started NAPA (Network Against Psychiatric Assault). It was really exciting. We had a march. We marched on Topeka State Hospital. And I remember there were two people who came to the march who hadn't been to the conference and they said, "We heard about this on the radio this morning and we just knew we had to be here." That was great.

DP: Were they ex-patients?

JC: Yeah. And those conferences continued until '84... '85 was the last one, when the first Alternatives Conference was. And that was a big clash. That was when the whole thing came to a head about government money and sell outs and....

DP: So, how did that happen? How did it go from being independent to being Alternatives and being funded by the government?

JC: Well, it didn't...I mean, one died and the other started, it wasn't absorbed by it.

DP: So it wasn't that people just said there's no point in having this one if they're doing Alternatives...or was the other conference dying?

JC: Well, it was already dying. It was one of those...the Conference on Human Rights and Psychiatric Oppression was a very weird. It had this ideology of total egalitarianism which is one of the things that never worked in practice. One of the principals of total egalitarianism, according to how this conference got organized, was you were not allowed to set up a schedule beforehand.

DP: (Laughing)

JC: So you spend three days arguing about what the schedule should be and about half a day trying to do it.

DP: Okay. I see (Laughing).

JC: And there was a lot of ego tripping, and they were always very weird, but they were also very exciting. I remember the year we had it in Florida. So that's probably '77 maybe, '78, '79. This woman from the Dutch group came and she wanted us to have

a big meeting so she could address the meeting about what the Dutch group was doing. And people said, "Well, you can't do that. You can't tell people that they all have to come to the same meeting." She couldn't figure that out. We said, "We'll have a workshop and anybody who wants to come, can come." "But I came all the way from Holland to talk about this," you know. But then, they were run on a shoestring. We had no funding. The first one in Detroit was in a university in the summertime 'cause this Hertzberg guy had connections there. The one in Lawrence, Kansas was in a campground. We did a few in campgrounds. We did one in Berkeley in a campground. We did one in Los Angeles in a campground. We had one here which was at Tufts University. We had one in Philadelphia which was at a university. But they were run on an absolute shoestring. People would get there if they could manage to...the biggest one was maybe 150 people. I remember there was one held in Ohio. That was one of the very few that I missed. I had hurt my back. I couldn't go and it was in a campground. And there's no way with my bad back that I'm going to manage the campground. And it was put on by some people, they were ex-patients but they were working for the Ohio Legal Rights Service, so they had made it a little more structured than normal. And the regulars were just outraged. "These terrible sellouts and they don't understand. Blah, blah, blah." And there was screaming, carrying on.

DP: Yeah, that sounds familiar.

JC: Renee Bostick was one of those folks. Do you remember Renee?

DP: Yes, I do.

JC: She was being accused at the top of people's lungs...people who had never seen her before, of being a total sellout and blah, blah, blah. But they always formed new groups. People would come to it like Sally Zinman came to one. She came to one in Philadelphia in '77 and two years later she hosted one in Palm Beach, where she was living, and meanwhile she had started a group and all that. That's why I always joke with Sally that she's the new kid on the block. I remember her first conference. (laugh) You know she's one of the old timers (laugh). To me she'll always be the new kid on the block.

DP: So how did people hear about this? Just sort of grapevine....

JC: Well, "Madness Network News," was our organ. You know, it's so amazing. I mean, we organized without e-mail and fax machines, when long distance was expensive.

DP: Yeah.

JC: You just sort of rationed your long distance calls and there was no e-mail. And there were no fax machines...so it was difficult.

DP: So, when do you think things changed? You were talking about the Alternatives Conference...

JC: So then in the early eighties, CSP (Community Support Programs) started having conferences and they were inviting ex-patients. We sort of invited ourselves to the first few and then they realized, we ought to invite some of these folks and so they started having CSP conferences. So, a lot of us used to go to those.

DP: And that's Community Support Program?

JC: Community Support Program, yeah.

DP: This was coming out of NIMH at the time?

JC: It was before the split. It was still NIMH. But CSP was this interesting group of people. I mean, they really did have a sort of ideology that, while it wasn't our ideology, was definitely opposed to the prevailing views in mainstream psychiatry. They thought that people ought to be able to live and mobilize in the community and get support. So, a lot of us started going to those and I guess...I don't know exactly where the idea came from, that we wanted them to fund a conference for us and so that was the first Alternatives Conference.

DP: And where was that?

JC: Baltimore.

DP: And what was it like?

JC: Well, it was...well, it was also very weird because it was about two months after the Human Rights and Psychiatric Oppression Conference. So, at that point there was some talk about trying to start a national organization.

TAPE 2, SIDE 2

JC: Yeah, so there was this Steering Committee for the Alternatives Conference and one of the things that they were talking about doing at the Conference was setting up some sort of national steering committee. And those of us who had been in the movement for a while, who had been going to these, we said, "Look, there's this thirteen year history of these annual conferences, you have to honor that fact and allow for some participation from that group of people whose been doing this all these years." So that was controversial.

DP: And who was setting up this committee?

JC: The grant was through On Our Own of Maryland, but our dear friend Joe Rogers was very involved and, anyhow...we went to the Alternatives Conference that year. There were two factions. One said we should take part in this process and get involved and reach a larger audience, and the other said you shouldn't do anything that involves government money. So there was a big battle about that.

DP: And which side were you on?

JC: Definitely that we should be involved. We need to reach out to more people. You know, we were this little group of people who met every year and talked to ourselves. So when we went to the Alternatives Conference, there was this whole bunch of people saying, "Who the hell are these folks from Vermont, and why do we have to listen to them?"

DP: And who were the people from Vermont?

JC: Well, it wasn't people from Vermont. It was the conference, because the conference had met in Vermont.

DP: Oh, I see.

JC: So I remember the big issue there became, does this group take a stand on involuntary commitment? If we're going to form this group, what does it stand for? Of course, there were all these people who didn't want to take a stand on anything. They just wanted to have a group.

DP: For the purpose of...?

JC: I never could figure that out. So that led a couple of months later to the founding of the two competing organizations, NAMP (National Association of Mental Patients) which became NAPS (National Association of Psychiatric Survivors), and NMHCA – National Mental Health Consumer's Association.

DP: And this was?

JC: 1985. Yeah.

DP: So that was the first attempt at forming a national organization, and it ended up with two...

JC: With two and a lot of bad blood. You know, Joe being Joe and doing his thing and, um...

DP: And who got the money?

JC: Well, there never was any money for the national organizations.

DP: Oh.

JC: The Alternatives Conference...

DP: (Over talking) Oh, the money was for the conference.

JC: For the conference.

DP: And who had control of that?

JC: NIMH let out as a contract every year to a group. And that's still how it's continued to be done. The word is that there's going to be one more and it's going to be done by CONTAC again.

DP: Oh, because I had heard there wasn't going to be one this year.

JC: Well, that's what we hear now. There's probably going to be one more.

DP: And why do they get to do it?

JC: Because they're the nice group...you know, they're the nice guys and don't make waves. Although we're just as happy not to do it. It's a pain in the ass. But, it was actually a very good conference this year.

DP: Was it?

JC: It really was. It really, really was. I was surprised. First of off, they invited David Oaks to do a keynote. Well, it was supposed to be David Oaks and Justin Dart together.. And David gave this really rousing, activist speech. And I noticed this when I went to Kansas, too...I did a Kansas state-wide thing in September or October...September, I guess. There are a lot of people now, even though they are not, you know, rabble rousing activists, and they're maybe still involved in the mental health system, but they have these groups that really seem to...stand for something. And they are outspoken and they're...maybe not activists. But they're advocates. They really believe in rights and dignity and that people should be treated with respect and that there's something wrong with the system. Maybe they don't think as many things are wrong with the system as I do...

DP: Right.

JC: And that's really a big change.

DP: And this is what a lot of grassroots activity?

JC: Yeah, yeah. Because I used to hate going to the Alternative Conferences. I remember one in Utah. There were all these people there. This is true of a number of the early conferences, but Utah is the one that struck me the most. There were all these people there who had literally been bused in from some program and who had no idea where they were, why they were there and when they were going home. They were just sitting there smoking cigarettes. They weren't going to meetings or anything. You know, they were going to meals and sitting outside smoking cigarettes and wondering when the van was coming to take them home. I just thought that was the cruelest thing. It's not like that anymore. There are all these people who, well, maybe they take medication, maybe they believe they have a mental illness, but they're advocates. They want to make the system better. That's not my thing but I respect that. I want to make the system better as long as it exists...I've always said you have to do both. You have to have a short term goal and a long term goal. And I certainly don't want people to be suffering now in the system as it exists, but I don't want the system that exists to go unquestioned either.

DP: To go back to when there were two national organizations. Do you think that was really based on philosophical differences or personality or both?

JC: Both. It was both. I mean, Joe was not going to take a backseat to anybody. It was going to be his organization, his way.

DP: Right. And at that time who was head of, of NAPS or...it wasn't called NAPS then it was...

JC: It was NAMF when it first started. It became NAPS about a year, year and a half later. Rae (Unzicker) was the secretary or coordinator or something like that. She said she would do it for six months and she ended up doing it for eight years or something, until the organization died a merciful death. There was this sort of a steering committee...

DP: Ah huh.

JC: Me and...who else was on it...Wendy Kapp, George Ebert, and... I can't even remember.

DP: Can you talk about how you met Rae Unzicker?

JC: Rae and I always remembered this slightly differently. I remember I was slightly politer than she thought I was. (laugh) Slightly. Just slightly. We met at...well,

NAPA, the group in San Francisco-The Network Against Psychiatric Assault- used to hold these gatherings at the Esalen Institute in Big Sur. The guy who started the Esalen Institute, whose name I can't remember, was actually an ex-patient, a very rich ex-patient.

DP: Ah huh.

JC: And he used to make the facilities available to them and it was a great place to have a gathering.

DP: Yeah.

JC: It was on cliffs perched above the Pacific Ocean and the wonderful organic food... So I got invited to one of those. And so did Rae. And I had heard about Rae. I'd seen something she'd written, and her group was affiliated with the Mental Health Association. That's how she got her group started in South Dakota. I just thought she was this— not having met her— I just thought she was this nice, reformist type. So I didn't feel super good about her...but I knew she was going to be there. Anyhow, we met outside one of the cabins. And she was smoking a cigarette and I said to her, "Are you going to smoke that in here?" She said I said it slightly ruder than that (laugh). And she was not intending to bring it inside. She was smoking it on the porch. But... we hit it off practically right away (laugh) from that, you know, abstentious beginning, when I discovered she was not a liberal reform- minded type at all. She and I just clicked with each other. So she was another one who was just absolutely single mindedly against forced treatment. If it's not about that, then why bother? And that's always been my belief.

DP: Joe Rogers was always a reformer?

JC Well, see, Joe, was always...right now Joe is a flaming radical. But Joe was always whatever...

DP: Excuse me?

JC: According to Joe, I mean. Right now his public stance is anti- forced treatment. But he's whatever he thinks is going to get him what he wants. I'm really beginning to wonder, because it's been a while now. He really has gotten away from some of his aggressive belligerence - he's been pretty decent for the last couple of years. He's been...he doesn't throw chairs and he doesn't, you know, scream. And he also has better politics. I don't know if he's really changed or if this is just, you know, because he's taken so many different positions on this stuff...

DP: Yeah. I'd be suspicious...

- JC: I'm always going to be suspicious. But he does seemed to have mellowed. Mellowed and become more radical at the same time if you know what I mean.
- DP: Yes, I do.
- JC: (Chuckling) Yeah, the issue, when there was this attempt to start this national organization...there was a meeting...let's see...the Conference on Human Rights and Psychiatric Oppression was probably in about September or so, August maybe...and the first Alternatives was maybe in October, and then there was this other meeting that came out of it which was the Steering Committee thing which I sort of invited myself to. I deliberately stayed off the Steering Committee 'cause I didn't want to get caught up in some of this crap and I kind of finagled my way into the meeting. It was held outside of Philadelphia somewhere. And that's when the whole thing came to a head about what is this organization going to stand for. And different people had been assigned to write these different position papers and Wendy Kapp...did you ever meet Wendy?
- DP: I don't think so, no.
- JC: Oh, Wendy was wonderful. I'm so sorry she left the movement. She was really wonderful. She wrote the one on forced treatment and it got voted down...but it got voted down in this parliamentary maneuver, you know. It wasn't straight forward, what was going on. And so then there was this big split and a group of us said, we're not going to be part of this organization. There was Rae, you know, the usual suspects. Rae, me, George, Wendy...in the back of the van that Joe was driving to take us all back to the airport or whatever. Allen Markman...
- DP: So you said a few minutes ago that eight years later it died a merciful death.
- JC: Yeah.
- DP: What did you...
- JC: These two organizations...they never had any money.
- DP: Right.
- JC: They spent most of their energy badmouthing each other.
- DP: Yeah.
- JC: We do still need a national organization but it's still... I still don't see how one's going to get formed. And the other thing that happened during that whole period was the rise of NAMI (National Organization for the Mentally Ill).

DP: Yeah.

JC: And most legislators, when they hear about mental health stuff, they hear about it from the American Psychiatric Association, National Mental Health Association, Bazelon Center and NAMI. And they think that's the whole...

DP The whole spectrum?

JC: Yeah.

DP: So why do you think it's so hard for us to organize a national organization?

JC: For one thing ,I think that the money for a national organization has to come out of people's pockets. At the Alternative Conference this year, they organized this trip to the Martin Luther King Center and that for me was just an absolute high point. And there was a workshop at the Conference about the civil rights movement. And it was the middle class people of Atlanta who bankrolled the civil rights movement. They weren't going to come out and march. A lot of times they didn't want their names associated with it because they had businesses, but they bankrolled it , they donated considerable sums of money at that point.

DP: Ah huh.

JC: You know, somebody who could give five hundred or a thousand dollars at that point.

DP: Right.

JC: We have to find those folks. We can't bankroll it out of the pockets of people who live on Social Security and that's always been our big failing. That we have not reached out to all those people out there who know they're ex-patients, who have all those feelings but are not public about it. And until we find those folks in sizeable numbers who can begin to put money into it...because you're not going to get a grant for this.

DP: No, you're right.

JC: Even if they won't put their names on it. Even if they say, I don't want to be actively involved, but here's a thousand bucks and I'll give you another thousand in six months.

DP: And the thing is there are so many people like that, but finding them...

JC: Yeah.

DP: Finding them systematically is...

JC: Right.

DP: ...is difficult.

JC: And that's, that's where you got to get the money from.

DP: Yeah. So you think it's basically the money. It's not either ideology or lack of ...

JC: But I wouldn't want to be part of a national organization that didn't stand against forced treatment. But, yeah, you need the money to do the mailings and the... and probably you could even get grants if you did it right. I mean, AAPD has been very successful at getting grants and AAPD is a model for what we need to do.

DP: Can you spell out that acronym?

JC: Oh, I'm sorry. The American Association of People with Disabilities. 'Cause that's the other direction my work has taken in the last ten years or so is doing all this cross disabilities stuff.

DP: Can you talk a little about that?

JC: Sure. You know, in a lot of ways the physical disability movement and our movement kind of went along on parallel tracks for a long time without really knowing about what one another was doing. We were doing very similar things. 'Cause even though they're not dealing with forced treatment-as a matter of fact one of the big issues is denial of treatment-they're dealing with a system of medical domination of people's lives.

DP: Yeah.

JC: A lot of disabilities may be medical in origin; a lot of disabilities aren't. If you're blind, that's not a medical condition. But, if you have an accident and become a quadriplegic or something, there's a medical component to that. But that doesn't mean the medical profession should run your life and that's pretty much what the medical profession has tried to do. And most of the people who got real active in starting the physical disability movement were rebelling about medical control of their entire lives.

INTERRUPTED BY PHONE CALL

JC: I was going to say that the issues are so much the same. It's about medical control of your life and why you can live your own life and be like other people and do ordinary

things. The guy who started the Berkeley Center for Independent Living, a guy by the name of Ed Roberts, he was a post polio survivor. He was one of the people most severely disabled by polio I've ever seen that lived. He was a quad. He was ventilated dependent. He slept in an iron lung. So he lived his adolescence in this hospital/school and he was, he was a kid. He was a teenager. He wanted to go out and do stuff, you know. And he and a bunch of other people who were there, they decided they wanted to go to college. They wanted to go to the University of California, which was a whole big issue because at that time there was no wheelchair accessibility and all that stuff. But they got admitted to the University of California, and the condition was that they had to live in the infirmary. I think that lasted one semester because they just wanted to be people. You know, we just want to do stuff. We want to live. As a matter of fact, when Ed was trying to get the money to go to college, he applied to the California Vocational Rehab and they evaluated his case and said he was so severely disabled he would never be able to work so there was no reason why they should support him to go to college. So, I don't know where he got the money to go to college. But he later became the Director of the California Voc Rehab (chuckle).

DP: That's poetic justice.

JC: Yeah. So, those were the issues. People wanting to live their lives and not having other people say, "Well, because you can't do this or because you have this diagnosis, this label or whatever. The first meeting I went to, the first cross disability meeting I went to, was a little invitational meeting. It was one of those, "Hey, we've got a pot of money left over, what can we spend it on?" And I got invited to this small meeting where people would talk about...I forgot what the exact terminology that they were using at that time was...self determination...or some phrase like that, on a cross disability basis. And I'm going to this meeting and I'm thinking actually these people aren't going to understand my issues and they're not going to get it and blah, blah, blah. And who's at this meeting...I met all these wonderful people. I met Ed Roberts. I met Bob Williams...I don't know if you know Bob Williams. He was...

DP: No.

JC: He was, well, later on he became one of the Clinton appointees and he was running some big Federal agency. But another real wild activist. I think Justin was at that meeting, too - Justin Dart.. And just wonderful people, you know. I had no problem getting my issues across. It was just a wonderful introduction to cross disability. I just got more and more interested in seeing those issues merge.

DP: And so your first experience was with people who did get those issues?

JC: Yeah, they just...

DP: Have you run into other parts of the disability movement that don't get our issues?

JC: I've run into people who don't get our issues, but by and large the leadership people, get them totally. The people I've met, they do. And I just have had real good experiences and the issues just seem so similar. And around the issue of your diagnosis not controlling your life. It's about wanting to do the things other people do and wanting to do things maybe a little differently. And it's about freedom and independence, not being limited. So to me, it's just always seemed very clear that it's the same. And there were people on both sides, you know. "Oh, I might not be able to walk, but I'm not crazy," on the one hand, or, "But those people have something wrong with them," on the other hand. We just have this label and we just have to get the psychiatrists to stop labeling us and everything and we'll be okay.

DP: I certainly heard people say...other people with psych histories say, "I don't consider myself disabled, so what do I have in common with them."

JC: Yeah. But...

DP: But even if you don't consider yourself disabled...

JC: The society does. Yeah. And one of the things I got introduced to...Steven Brown was another one who was at that meeting, another wonderful theorist. There's this whole thing in the disabilities community which was the social construct of disability. That disability is not a medical condition. It's not something wrong with you. It's not something that resides in the individual. It's society making assumptions about certain people based on characteristics. It's just like racism.

DP: Ah huh.

JC: So, once you understand that model, then those problems just go away. And there are examples of this. We should get up to Nantucket or Martha's Vineyard, where in the 1800's there was this huge number of people who lived there who were deaf, because it was a small self-contained community. It was some genetic thing. And so being deaf was the norm, and a lot of people who weren't deaf learned sign language because there were so many people who were deaf. So, you know, what's a disability is very culturally determined.

DP: Yeah. How did you get involved in doing international work?

JC: Oh, it was just something that kind of grew. I got invited to... well, we had met this woman from Holland who came to one of the human rights conferences, so I had a contact there. And I got invited to a professional meeting in England. So I got to meet some of the ex-patients from there. And somebody else invited me to Australia. It just kind of happened. And I never thought I'd be the kind of person who got to travel abroad and stuff, and it was just real exciting and I loved it. And one of the

things I found out when I started meeting people from other countries was the experience of being a psychiatric patient is so universal. The experiences are so the same in terms of...(PHONE RINGS) Jesus, this phone is not going to stop ringing.

DP: International work...

JC: Yeah, so the experiences are so much the same that you talk to people and it's all about not being treated like a human being in the institution. Being discriminated against outside the institution. Every place I go people say, "In my country, there's a particularly bad problem with stigma." So I tell them it's not just in your country. 'Cause everybody says that.

DP: What do you think about the use of that term?

JC: I don't like the word stigma at all. Stigma, it's, again, creating the problem within the person, and I much prefer discrimination. That's another big thing we have with the disability movement. There's a tremendous amount of discrimination against people with disabilities. I just went to this big international conference in Japan and there were a lot of people from third world countries and there are people with disabilities. They don't get to go to school. They can't work. They're prohibited from working or they can't work because they can't get out of their houses. Or they're not allowed to marry. Or, either they're not allowed to marry legally or they're not allowed to marry because of prejudice. Or, they're not allowed to have kids, or the kids get taken away from them, and on and on and on. Or they're told they should work in sheltered workshops. I met this really neat woman from Ghana who was blind and she didn't quite get my thing. We started talking and I just kept making all these analogies and she said, "Yeah, that's true. I wanted to go to university and they wanted me to make baskets."

DP: Yeah, that sounds familiar.

JC: Yeah. So there's always other people saying, "Oh, you have a disability. Here's what your life is going to be," and it's going to be some crummy life. Well, why should you want that?

DP: Is there anything about the history of the movement that I haven't asked you about that you think is important to record?

JC: Oh, God. There's just so much. I think we really have to get back to doing the more confrontational stuff. The civil disobedience.

DP: I noticed something on the SCI website about a hunger strike.

JC: Yeah, there's talk about doing a hunger strike.

DP: Can you tell me a little bit about that?

JC: Yeah, well, it's still sort of in the formative stages. But I'm not sure how to frame the issue. I mean, I'm not sure if we're framing it correctly, and whether this is really going to fly, 'cause the idea as it stands now is to do it around trying to make the psychiatric profession either produce evidence or admit that they can't produce evidence that mental illness exists. And I think that's too amorphous. But we have to do something to get this thing out in the mainstream. Nobody seems to know its there. You hear something about mental health in the media, it's going to be an NIMH position or drug companies or...

DP: The media, even the progressive media, doesn't get it.

JC: Yeah. NPR, they're absolutely awful. And PBS, the same thing. You know, people who really should understand...

DP: Well, one of the things I've always wondered about the movement is, in a lot of circles we have a reputation of being angry and confrontational, etc., etc., but I think we're way too polite.

JC: Ah huh. I agree. I think one of the greatest pieces of our history that very few people know about was the California group that sat in Governor Brown's office for a month.

DP: For a month?

JC: For a month.

DP: Wow.

JC: Over deaths in institutions, and they wanted a meeting with him.

DP: And they didn't throw them out?

JC: No, well, it **was** Jerry Brown, you know (chuckling).

DP: And what happened?

JC: They got an investigation and some facts were brought to light. But even the fact that they did that and they stayed there for a month...how many people know about that? And we've got to do stuff like that.

DP: I always think one of the reasons that we don't do stuff like that is that we all know that since we have a history, somebody can use that to lock us up.

JC: People will just call us nuts. I don't think we'd get locked up. But I think people would just dismiss us. You know, we're just crazy.

DP: Yeah.

JC: But, look at the stuff ADAPT does. That's an activist disability group, they can do such great theater. I mean, people in wheelchairs sitting in and all that. It just makes good television. What can I tell you. Or getting out of their wheelchairs and falling, which is one of their things that they do a lot.

DP: I still believe we could learn some stuff from ACTUP, too...

JC: Yeah. ACTUP and ADAPT are really good models. I totally agree with you. I think we have to start doing that stuff because in a lot of ways things are getting worse.

DP: Oh, yeah.

JC: I mean, we were talking before we put the tape on about the evidence based practice stuff...

TAPE 3, SIDE 1.

JC: We're got to get this stuff into the public eye somehow. Because if we do that, it's going to have a synergistic effect because not only is it going to get our issues noticed, but it's going to bring out of the woodwork a lot more people.

DP: On the other hand, you could speculate that there is some kind of...well, conspiracy is too strong a word, but there is basically...the media doesn't...

JC: Doesn't care.

DP: ...doesn't care, or they only hear from the mainstream. Take, for instance, Bob Whitaker's book, "Mad in America, a respectable book written by a respectable journalist with a lot of research in it, and it can't get reviewed in *The New York Times Book Review*. So, I think there are some clear and deliberate roadblocks.

JC: There's a lot of power and money at stake and there's an orthodoxy.

DP: Although it's weird, because it's actually a rather recent orthodoxy. This whole thing about biological brain disease isn't all that old.

JC: No, very new. But on the other hand, there's been some belief that it's biological for a long time. Even Freud said that there was a big difference between neurotics and the psychotics and that he was sure that there would be something found.

DP: And they're still looking.

JC: I know and they're going to keep looking because it doesn't exist.

DP: And I just found that really interesting because the people in charge get up and say, "Oh, it's definitely biological." And in the next breath they'll say, "And we expect to find this gene any day..."

JC: Yeah, and they've been expecting to find it for fifty years.

DP: Yeah.

JC: And that's the idea behind the hunger strike, to try to make them admit publicly that the evidence isn't there, and it's all theory. Then, of course, they'll say it's like the theory of evolution is a theory. But that's why I don't think that's a good way to frame the issues.

DP: So, what do you think would be better?

JC: I'm not sure. Somehow about involuntary commitment and forced treatment more than about the existence or non-existence of mental illness. But I'm not sure quite how to frame it. But you need something that you can explain to people in a sound bite. And you cannot explain the argument about the existence or non-existence of mental illness in a sound bite. And all public discourses are conducted in sound bites these days. But, yeah, we've got to find a way of getting these issues really out there.

DP: One other thing I think is that a lot of the mainstream human rights groups don't understand our issue as a human rights issue...

JC: Right. But they don't even think that disability is a human rights issue. One of the big efforts going on right now is to get the mainstream human rights groups to recognize disability as a human rights issue. And actually, we might be getting somewhere with Human Rights Watch. Human Rights Watch just issued this report on psychiatry in China, which is like the psychiatry in the Soviet Union stuff. There's this dissident that they're keeping in a mental health hospital with all these crazy people and both Support Coalition and the wonderful international organization, World Network of Users and Survivors of Psychiatry, wrote to Human Rights Watch. And I heard through the grapevine that our letter reached the person at Human Rights Watch who was primarily responsible for this report and she really felt that we were on to something.

DP: Because I was just dumbfounded by that whole report, where basically they want the psychiatrists to go in there and investigate This is asking the fox to guard the chicken coop.

JC: Yeah, sure. But anyhow, we might be getting somewhere with them. There was a meeting in Washington this past spring with disability people and human rights people. Of course the things the human rights people were saying were horrible, 'cause they don't get it. One guy kept talking about people afflicted with disability. But, you know, we're trying, and certainly MDRI- Eric Rosenthal's organization - is really trying to bridge that gap. That's what he sees as his mission is to try to bridge that gap. And the attempt to do this UN treaty, which would be a human rights-based treaty and get disability out of the area of welfare and medicine and into the human rights arena. So there are some people who are in the human rights community who are beginning to get it a little bit. But certainly that's got to be the effort, to make this a human rights issue.

DP: In a lot of ways on a national level and certainly in many states, it feels like things are really going backwards in the last few years. Can you talk about why ...

JC: Well, I was actually very impressed, like I told you, when I went to Kansas in September, I guess it was...and here's all these people who are...they're real advocates. They really have a clear point of view about how people are not being treated right and how can things change. And I don't think they believe it needs to change as much as I think it needs to change, but that's just a matter of degree. So in some ways, I think we have more of a core of activists than we used to have. But in other ways, I think that the mental health system is going backwards so rapidly.

DP: Yeah.

JC: More drugs. More coercion. More control. And all the states being in financial trouble is only going to make that stuff worse, 'cause what gets cut in those situations are the things perceived of as frills.

DP: Right.

JC: And so you have more people ending up in emergency rooms and more people needing acute care.

DP: It ends up costing more...

JC: It ends up costing them more money and it ends up being the worst kind of treatment. So in a lot of ways things are getting worse.

- DP: Do you think that the increased coercion is in any way a backlash against the kind of things that are advocated by the movement?
- JC: I'm not sure. I mean, the society is becoming more coercive. I mean, look at what's happening to the country right now. We've got massive violations of civil rights and nobody is raising a peep. Justifications for holding people without trial. Holding people without charges. Without access to lawyers. And, you know, people think that's okay, it's just crazy Muslim radical extremists. So, you know...
- DP: So what do you think the answer to this is? I mean, we talked a little bit before about we need to get the issues out in the mainstream...
- JC: The issue is that a diagnosis of mental illness carries with it a massive loss of civil rights and of social status. And so, it's not about making the system nicer or making treatment better, finding better treatments. As long as people can still lose their basic citizenship rights because of what's supposed to be a medical condition or medical diagnosis, that's where the problem lies.
- DP: Can you talk about how the National Empowerment Center started and what your involvement with it has been?
- JC: That's kind of strange how that started. There was a little group of people who Bill Anthony brought together at B.U., all of whom were ex-patients and who were talking about what we would like to see different. It was a sort of a little think tank. As a matter of fact, we used to call ourselves the "dream team" because we had no agenda other than talking about what we would like to see changed, and theory and philosophy and, you know, nice stuff to sit around and talk about. And who was in that group...Dan, me and Pat Deegan. Five or six people. And then one day, Bill came in and said, "CMHS has this grant that they're giving out for technical assistance. Maybe this is something this group wants to pursue." So all of a sudden instead of being this group of philosophers, we started going after this grant. And the idea of trying to become a focal point for information and knowledge about empowerment seemed to us to be a good way of reaching people.
- DP: And what year was that? When you were first funded?
- JC: I think it was '91. Oh, I know something we didn't talk about at all, which grew out of one of the Conference on Human Rights and Psychiatric Oppression, was the national teleconference.
- DP: Ah, yes.
- JC: We had that for...we must have had that for five years.

DP: I remember the first time I ever heard about it, hearing it called the “Judi Chamberlin teleconference.”

JC: (Laughing) I never called it that.

DP: No, but some people did.

JC: And that came about at the end of one of the Conferences on Human Rights and Psychiatric Oppression. We were all sitting around talking, you know, sort of one of those closing things. What would you wish could happen? And I think it was Allen Markman...no, no, it was Paul Dorfner, who said, “I wish we could be together all the time,” and that resonated for a lot of people.

DP: Yeah.

JC: And he was into all this communication stuff and he was actually running a statewide teleconference in Vermont. And somehow we got the idea that for a very small amount of money, we could run a national teleconference and all talk to each other once a month.

DP: And so where did the money come from?

JC: That came from, from CSP...Community Support Program. And I went into Bill Anthony, because I was working at BU, and I said, “Could I run this out of this office,” ‘cause my job there was trying to network ex-patients. And we did that for five years, I think. That was fun.

DP: And so why did it end?

JC: It just kind of petered out. I guess because the technical assistance centers were starting, which were going to do things in a little more formalized way. And it also broke down...there was a lot of factionalism.

DP: You know, that happens a lot.

JC: A lot of it has to do with a particular individual (chuckle).

DP: It does. Sometimes I wonder, though, because clearly that’s an issue for all kinds of movements....

JC: Yes, yes.

DP: ...and on the other hand I think it’s worse in our movement than others.

JC: Yeah.

DP: And I think some of that is because there are people who gravitate towards our movement who, frankly, I don't think are really mental patients. I think they're con people.

JC: (Laughing)

DP: And they're just disruptive.

JC: And it's also about people who have been powerless...some gain a little bit of power and get drunk on it...

DP: Yeah.

JC: ...and that happens in a lot of movements.

DP: Well it does. But I think a lot of movements outgrow it.

JC: Ah huh.

DP: I'm not sure that we have yet.

JC: I think it's getting better.

DP: Have you read the initial report from the President's Commission...

JC: No, I don't want...I don't really want to.

DP: I feel bad for Dan...

JC: It's an awful position to be in. But I'm glad he's the one they picked. They could have picked someone who was a total sellout.

DP: Well, yeah.

JC: Because if that...what's his name...Fred Freeze...

DP: Hmm.... But on the other hand, they could have had more than one of us, too.

JC: Yeah. But as soon as you have more than one of us, than it probably would have been like Dan Fisher and Fred Freeze.

DP: Oh, yeah. That's probably so.

JC: The report will just say “We need more treatment... more treatment. More research. Not let people fall through the cracks. And the other thing is that with this new election, I’m afraid the Bush administration could put Satel in a real position of power.

DP: Like the head of CMHS (Center for Mental Health Services)?

JC: Yes.

DP: That’s occurred to me, too. That would be scary.

JC: That would be terrifying.

DP: The fact that they even put her on that advisory committee is scary enough.

JC: Yeah, but I think that committee has very little power. But I think they will put her in a position of real power.

DP: So at this point, is there already a determination that they’re going to phase out the TA centers...

JC: The TA centers, yeah...

DP: ...next year.

JC: Yeah, so the TA centers will be gone. Satel is just one person on that advisory council, but she’s got a direct line into the White House. And you read the stuff that she said at that meeting?

DP: She’s scary.

JC: Yeah. “Why are we listening to these consumers? Why are we spending all our time listening to consumers?”

DP: Plus it was my understanding that they’ve moved a lot of the services research out of CMHS and back into NIMH?

JC: Ah huh. Well, some people think that might be a good thing.

DP: Really. Why?

JC: Because NIMH research has more prestige, and if we can get them to research some of the right things...

- DP: Well, that's a big if. Because I often think they have a hard time seeing past the medical model and past a purely quantitative research approach.
- JC: Yeah.
- DP: I mean, it kind of looks like CMHS had the legs pulled out from under it anyway.
- JC: Yeah. But BU is going after some NIMH grants.
- DP: Yeah. Well, that's good. But the possibility of Satel, that certainly has crossed my mind. That would be a nightmare.
- JC: Yeah. She wants to silence us. It's not these polite little people who say, "Oh, yeah, what you've got to say is important." They don't listen to us anyway, but they at least think we have a right to speak. She doesn't think we have a right to speak. You know, she called it in her book, the inmates running the asylum. She's a scary lady 'cause she's smart.
- DP: Yeah.
- JC: These are the worst of times. I was really depressed yesterday when I listened to all that election coverage.
- DP: Oh, God. I was just..."What country can I move to?"
- JC: Yeah, we couldn't listen on Tuesday night. Terry and I are both news junkies and he said during this, let's go to bed.
- DP: I know, I couldn't listen to it either. So, do you think that in the current political environment that our message, from a rights perspective, could resonate with the general public?
- JC: If your issue is human rights, then your issue is human rights in the good times and the bad times. And, you know, mental patients have been so successfully demonized.
- DP: I've always wondered why there wasn't more uprisings on wards. It's probably because people are over-medicated.
- JC: They're scared and demoralized, and probably there have been. You know, it's like slave rebellions. We don't know too much about those, either.
- DP: That's true.
- JC: There were a lot of them.

- DP: So do you think things are better or worse (or how are they different) for people who get caught up in the system now, as opposed to when you were hospitalized?
- JC: I think they're worse. I think they're worse. I think the system is more coercive now. I think it's harder to get out of the system now. There's more drugs. They're drugging people earlier and earlier in life. There's this whole thing going on now about how many people start college after taking psychiatric drugs for years. We're seeing more and more problems being medicalized. I mean, they're advertising psych drugs on TV. People are just being told all the time that every human problem is a chemical imbalance in your brain and you need drugs to fix it.
- DP: So are you planning to write another book?
- JC: I don't know. After Highlander this year, I got really fired up about an idea, but I haven't really pursued it. This idea about trying to draw parallels between the apologists for slavery in the pre-Civil War era and the apologists for psychiatry. And it was all for the slave's benefit. And, of course, what they had to say was... (chuckle) not listened to.
- DP: But you've done a lot of writing over the years.
- JC: Yeah, I do lots of pieces.
- DP: Have you thought about putting together an anthology of your pieces or anything like that?
- JC: That's another possibility. You know, it's getting very hard to get things published these days.
- DP: So, what do you see going on now that is hopeful... 'cause we've spent a lot of time talking about what's not so great.
- JC: What's hopeful? That there's a new generation of activists coming up. That's certainly encouraging, and that there are more younger people. Because for a while it just seemed like we weren't bringing in new people. We were just all getting a little older every year (chuckle). Now there really do seem to be a lot of good young people. That we're building these alliances. We're really building a cross-disability alliance. It's hard to be hopeful right now. Things are not good. More and more people are convinced that all these things are brain diseases, both labeled people and the unlabeled people.
- DP: You know, I've always felt in a lot of ways that you work for change because it's the right thing to do... not that you expect it to change in your lifetime.

JC: I think about it like it is this big mountain and different people are just chipping away. And you're just going to keep on chipping away, because it's important to you, and eventually it crumbles. But things do seem to go around in historic cycles. I mean, the modern psychiatrists look back on it and say "Before we thought these things were brain diseases, we used to blame the parents and stuff like that." Well, shit, it's not a question of blaming, but, you know, family dynamics have an awful lot to do with it.

DP: Sure.

JC: And in most cases...not out of deliberate maliciousness. Most cases just because interpersonal dynamics are complicated. And all the arguments that can be made for biology, you know, like siblings and stuff like that...can also be made for the family dynamics side of it.

DP: Do you think it matters what people think about the causes of so-called "mental illness" in terms of how they go about doing activism?

JC: Yeah, I think it does. I think that if you think it's a brain disease, your activism is going to take a very different form. But on the other hand, you know, if somebody thinks it is a brain disease and they still think that they want to work for human rights for people labeled mentally ill, I don't have a problem. I'm not going to kick them out. I'm not looking for any ideological purity tests. We're small enough as it is.

DP: Do you feel sometimes that words get put in your mouth and you get blamed for something you never said?

JC: Oh, yeah. Absolutely. I'm always told that I'm anti-drug and I tell people not to take their drugs. And certainly if somebody wants to go off their drugs, I'd support that but I don't tell them, "Throw away your drugs. Never take them again and everything will be fine," because that's sort of a recipe for disaster. I always get accused of saying that. Some times I'll give a speech and somebody will stand up in the audience afterwards and say, "But you said such and such." And they've just listened to me, you know. And I didn't say it. So people hear what they want to hear.

DP: Thank you.

JC: You're welcome. It's very interesting to talk about this stuff.

END OF INTERVIEW.