

Subject: Jackie McKinney

Location:

Date: August 22, 2002

Interviewer: Steve Periard

Jackie McKinney is being interviewed for her work as an activist in the Consumer/ Survivor/ Ex-patient Movement.

Hi, Jackie.

Hi. How are you doing?

I'm doing very well. First question - I'd like to first talk about your personal experience because I think in many cases that ties into your experience as an activist or leads you to that work. Where and when were you born?

I was born in Jersey.

And what year was that?

October in 1934 – October 18th actually is my birthday – 1934.

And what did your parents do for a living?

A. My mother at the time I was born probably didn't do very much. She was a young girl and, ah, um, my understanding about the role of my paternal parent – which had a great impact on my life – it's not one that I have very positive memories of. So I don't talk a lot about them – about him in a positive way because he's part of the reason that I ended up with the kind of life that I did because he was the person that was always abusing me.

Q. You suffered abuse?

A. Very early or, ah, very early probably as early as two years old.

Q. And, and this led you to be hospitalized –

A. Yeah.

Q. - and it was a home for crippled children?

A. That's right. I was hospitalized for a home for crippled children. In the first place, people could not identify – doctors couldn't identify, family couldn't – they couldn't identify what was quote "wrong" with me because I was a different kind of child sort of good at school but not good at life. I just could not really develop in a normal way and the stories I would tell they would say that it was some – that I was making them up. But I was really trying to talk about the abuse in a way that a child whose been denied the, the, um, truth. You know, as a kid that couldn't say what was really going on. Or if I tried to say it, you know, I was punished or, or ignored. But in some way I suffered if I tried to say that so my behavior in many instances had to do with just acting more physically ill than emotionally ill which I really was. So I ended up in this home for crippled children because I stopped walking at nine years old, you know. I just couldn't walk any more and I really think that was probably one of the smartest things that I ever did in my life because I think that was my way of saying there's something really going on here. This is – and I'm going to stop it one way or another. So I ended up in this home for crippled children – primarily white, actually all white and me until it was the first – it was really traumatic. Even though I was leaving one traumatic instance such as abuse. I was going into another one because – I came from a totally black neighborhood – doctors, teachers, preachers, lawyers – everything. There was only one or two but they were all African-Americans and all of a sudden I'm living in this totally white world and it was not easy. I missed the black hair, the black smells, the black food, the black laughter, the black jokes. I just missed my people and I think it was at that point I became aware of what I think the most positive parts of being an African-American. I missed the culture. I didn't have a word for it, but I knew I missed it. I knew I felt as if I had come into a new land and it was not a warm and welcoming land.

Q. You were the only African-American woman?

A. Child. Yes, and nobody else was there. I mean, all the staff, all the nurses, all the doctors, even the people that cleaned and cooked and delivered mail – all white. A new world for me. And my parent – my mother and my family could not visit me because this home for crippled children also took children who were in those days had something we called infantile paralysis but was also known as polio. And these children – and polio is contagious – so these children had polio and they were in this home. So when I went there I wasn't allowed to come out and people weren't allowed to come in because polio was contagious. But I didn't have polio. Well, I think it's just a play on, on the society because I think so often people with mental illness get misdiagnosed or get into the wrong place. We know them more as institutions. We know them more as

prisons. But, but it still – it happened to me very young. Wrong place, but whatever's there, you deal with it. Nobody was concerned with whether I got polio any more than if you are a prisoner and you go to prison and everybody's got tuberculosis and you're, you're a quad, you know. It's just life repeating itself. Just for me it was very early. Misdiagnosis and so misplaced and then further traumatized.

Q. So how, how were you treated because this is – there was no, seemingly no medical, ah, reason for why you couldn't walk.

A. Well, I was treated as if I had polio. I mean, I was treated the same way. My legs didn't work. My back didn't work properly so I had something they called a Sister Kenny treatment which had been invented by a nurse named Sister Kenny and they made these hot pads out of sort of old Army blankets – very heavy, held heat and they put a rubber pad on and put two or three layers of this heat and they heated the body. They were also very, very good about exercising the limbs that weren't working so that there wasn't – I don't know the word, but I know it goes A-T-R – atrophy?

Q. Atrophy.

A. There was no atrophy in my body which was why they knew I didn't have polio, you know. My body looked exactly – the children who had polio, their limbs withered and changed form. Mine didn't. But they didn't know what else to do so they just – I mean, I know it sounds macabre but they just kept treating me as if I had polio.

Q. So how long did you stay?

A. Well, I stayed – just let me say that in the midst of this sort of “we don't know what we're doing,” there came this young woman from another country who had been trained in both psychoanalysis and in physical and emotional therapy. So she was, um, she was there as an internship from either Sweden or Norway. I was really too young to really know very much about other countries but she came and immediately she looked at me and was instant. She said, “Ut oh, there's somebody that I recognize that something is going on.” And she took me on almost as a side assignment. She wasn't assigned to me but she tried to get assigned to me because she found out or she, she knew more about what was going on – what I wasn't telling than I was really able to talk about. And she took an interest in me and she spent a lot of time with me but it was unauthorized and so after a while someone spoke to my mother about it and, and then she said well she would try to get permission from my mother to allow her to work with me. And, of course, my mother not only said no to her but adamantly said from the window as I peaked out at her,

don't you talk to anybody about anything that goes on in your home. And that was the way I think so many African-American children are treated about abuse in their family. I think we're very secretive in our community about this issue of incest and sexual abuse. I think it's a hallmark of our, our being. Any how, she denied this woman the right to treat me and she said to them, "And no one ever, is to ever treat her for anything other than her physical issues. And if you do, I will take her out and just remove her." And, ah, subsequently that's what she did. You know, it just went on and on and by the time – it takes a long time for paperwork to go through the process and during that time this woman made a big impact on my life. I don't know the numbers. One of the things that I have as a part of my life style, cause of the things I've lived through – I don't do good with dates and numbers and names and things like that, but I probably – she probably had another two months to work with me and during those two months she absolutely convinced me that it wasn't what was wrong with me that I should be interested in but what had happened to me. That I had a story and that even though people weren't listening that it was true. She convinced me that I was telling the truth after my whole life had been nine years of convincing me that I wasn't telling the truth. She convinced me that I was telling the truth and that some day I would have an opportunity to live that truth – have that truth be lived – be part of my living openness – and probably saved my life. It was too late for her to change the way I felt about the rest of the world and when I did leave that home at my mother bequest, my mother just finally convinced them that she didn't want me there any more. I had learned to walk. So I was there maybe another eight or nine months after she – this woman couldn't work with me any more. I left the home. I learned to walk. I left the home. I wasn't walking perfect but I was walking and, ah – but something else came out of that hospital with me. Something that I remember to the day I die. I came out of that hospital not just myself but I brought a sister out and that sister was called rage. And I lived with that rage for maybe another forty, close to fifty years. It was the hallmark of my existence that rage. Because you see, before I was confused. I knew, but I was confused. So when she tried to free me the only weapon she left me with was rage. The knowledge turned to rage. And we have to remember that when we look at people, you know, and we try to help them. We have to look at what the environment is that's going to support whatever we're doing. So, that's the way I entered the world and for the next thirty, I mean, within five, ten years – I was nine when I went in to ten, eleven when I came out and by the time I was fifteen, sixteen I started having kids, started just being a whole different kind of person but the operational piece of me was the rage. Rage you saw first. Rage you heard first. That's who I was.

Q. Fueled everything that you –

A. Fueled everything. Even my inner thoughts were raging. So the mental health issues which were all there just got inculcated in that rage. Well, she just acts like that. She's so mad. She's so crazy. So this. And it was true. That's what happened to me.

Q. So, you're going through your life with this intense amount of anger – something broke at some point in your fifties – when you were in your fifties.

A. Oh, I lived a long, long life with many, many, many pieces before my fifties but it was in the fifties – in my fifties – probably in my late forties that I had a major break after having years of living all kinds of experiences in and out of being in hospitals – medical hospitals – for two or three days for this issue and that issue. Never with a real definition of what was wrong with me. Somewhere maybe in my late forties – maybe fifties – I got to a place where I just had – I cracked totally down the middle, you know. And I was victimized again in the streets of New York by a serial rapist along with a lot of other women who seemingly got over it. But I didn't. And because of my background, my history and lack of treatment I had a major break. My mama would call it a break down but it was a break up and I ended up living homeless in the streets walking away from the family, walking away from my husband, walking away from my house, my life and I never regained those things but I did regain my family. I regained many of my children, my relationship with them later. I lived homeless in the streets and ended up in Washington, D.C. and there I met a therapist and a group of women. In Washington, D.C. I met two different advocates, different kinds of advocates. I met women in the D.C. Rape Crisis Center who, ah, adopted me. I lived on the corner more or less, ah, and there was this store they would walk by. They were on their way to – when they went to work, they had to cross that corner. It must have been when they came off the bus or the train, I don't remember. But they would pass that corner and they would speak to me. I wouldn't speak. I wanted nothing to do with them. But over a period of time as it got closer and closer towards the winter, they began to encourage me more and more to come in, to go in, to do something and, ah, they went over to the store. It was really amazing that they didn't get through to me. They went over to the store and I used to go into the store and just take whatever I wanted to eat. Just eat. And so me and this storekeeper we were always fighting and he was a person from another country. His language was different and he looked different and so it was just a, just a very visible altercation all the time and the police would come but they – but what could they do to me? So anyhow, ah, these women, they went to the store and they gave him money. They said, "Let her eat. Just let her eat whatever she wants to eat." And they changed the way he felt about me. And after awhile when I would go and he would say, "Just go and eat. Go get it." And that

changed the way I began to feel about them. But they couldn't do anything for me directly. But when they changed the environment for me, then I responded and actually by the time that the winter really got into the cold, I was coming into their place and going over to the local hospital, sitting in the waiting room. I just began to be more protective and they talked me into going into a mental hospital to see if they could, you know, break through with some of this obvious issues that I had – that I was showing. And we went in the – went to the hospital – one of these elite hospitals there in Washington, D.C. and it was - George Washington University has a small unit there, maybe in those days twenty beds, twenty-one beds and basically used for doctor's wives and people who were a part of their elite and I was there because of the women who put me there. They were board members – board member from the Women Rape Crisis Center was affiliated – didn't work out for me. I was in and out of there over a very short period of time. It was just too elites for me. It just did not meet any of my needs. And then I ended up in St. Elizabeth's – the largest mental hospital in America – over in the other side of town. And that did not meet my needs because I was really afraid of the people with the – who were very symptomatic – but there I did meet my therapist, the one who worked with me for the next five years who saw me three times a week and who ended up being the person that helped me to rebuild from what I call the skeleton of myself. Who understood trauma. Who understood family violence. Who understood a life style of a lifetime of never getting treatment and really helped me to regain who I was and what I was and stop looking at myself from the rage point of view and really turned that rage out. Not out on people, but just got rid of it. Just helped me to redefine myself from another point of view to okay, rage has had its day. It belongs there but how about if there's another part. And her name was Lisa VanStrustran and she's a local psychiatrist in D.C. She saw me all those years without a penny, but she was a student of a Dr. Putnam. And Putnam was a person who was studying in what they called in those days "people with, with mixed personalities." Now, I did not so much buy into the mixed personality piece of myself although I know about MPD and DID and the different names that they call it, but what I did buy into was if I – if you saw me when I was drunk, I might act one way. If you saw me when I was drugging, I might act another way. If I was really deep sad and depressed, I would act another way. If you asked me about my life when I was thinking about when I was seventeen, I might tell you one story. But then if you asked me about it I talked forty-six, I'd certainly have a different life style – I'd been a middle class woman when that attack happened to me. I would tell you another story. So I think I feel in because of the stories – the layers and layers – I think traumatized women are like onions. There's so many layers that if you pull a layer, you get a different story. I don't think it was so much I was a liar as I was a de-liar. I wasn't a denier and I wasn't a liar. I was a combination. Because I

denied so much of what was real for me, I made up stories about it and it looked like I was lying, but those were, those were my self protections.

Q. At any time during your stay at St. Elizabeth's or George Washington, were you diagnosed?

A. I was diagnosed my whole life. Schizophrenia, of course, was the main diagnosis for African-Americans. That was the first thing they wrote down no matter what symptoms you were presenting. Trauma was never anything that was ever written down about an African-American woman. Trauma was kept for the very small segment of the population who could afford private treatment. But anybody who went into a public system never got diagnosed as having trauma or having anything that was related to a cause. You were just a mentally ill person, therefore, schizophrenia was the catch-all for everything. Yes, I had many, many diagnosis and the main was schizophrenia. And I also took medication for schizophrenia. A number of medications. Some new and some old such as the Thorazine. Thorazine, Thorazine and I remember that particularly because it was the worst medication that I ever had in my life. It made me feel as if I were a two hundred pound woman that had turned into a, a object as big as my, ah, finger – my forefinger and then I was down inside of my stomach screaming all the time and the image, and the picture in my brain – the way it made me feel – was so real that I couldn't talk because I was hoarse all the time from screaming and that's the impact of a medication. That it could make me actually feel as if I was going through their process and my body responded accordingly. So I couldn't talk. So they said, "She's not talking." It wasn't that I wasn't talking. I couldn't. I am screaming all the time. That was Thorazine. They never took me off of it no matter what. So I just stopped. Stopped going to hospitals. Stopped going to clinics and went back to doing what seemed to me my only recourse and had been my recourse for thirty, forty years – drugs and alcohol. Street drugs and alcohol.

Q. And in a way that was more effective in, in kind of helping you, um, deaden a lot of the –

A. Ah huh. We call it self medication in the Consumer Movement and I think some psychiatrists now use our term. It was our form of treating and deadening as you say – of dealing with. It was our medication. Ah huh.

Q. I'd like to go into, ah, your first experience with, um, taking on an activist role.

A. In the Consumer Movement or in the country – in New York because they were different.

Q. Actually, I'd like to talk to you about in your pre-interview, about welfare rights –

A. Yup.

Q. - activism.

A. Yeah.

Q. I think that's a good place to start.

A. Well, earlier in my life as I said, when I – after coming out of the hospital and having the children and having a really terrible relationships, I had discovered men, alcohol, drugs – all the things that can turn a young woman's head and add that to the emotional upheavals that I was living and the numbers of small children that I had – I was really, pretty much a set up for trouble – poverty and racism, ah, being what they were in addition to all my other issues. I found that I could no longer live comfortably in this city and it was my family that I wanted to leave and, ah, went to New York because I used to listen to Frank Sinatra and he came out with that song "New York, New York," and he said if you could make it there, you could make it anywhere. So I said I could make it there. I can make it anywhere. I went to New York and for the first time I got on public assistance. That was no acceptable in the small town that I came from. You didn't get any money for being poor there. You might have gotten a sack of grain, but you wasn't going to get any money. So, I got money – but more important, I got people who understood that being poor and having children and all the isms and all the outcast pieces still could lead up to having your rights. And so I joined Welfare Rights and became an activist both because they were willing to include me, but also because there were many people there in similar circumstances and because it dealt directly with me as a woman and as a mother – something I had never in my life been dealt with as a woman and a mother in a positive way. So I went there. And my first activism was in welfare rights fighting for the rights of other women and other mothers and it was a really, really mind boggling but life shaking and shaping experience. While I was in Welfare Rights there I also got into a training program – a training program for women like myself. The program was geared, was put together by a man in New York – Congressman Shauer, James Shauer, who was a very popular congressman from New York and he wrote this program called New Careers for the Poor. New York was one of the demonstration states and, ah, we were recruited to go to school and to go to work and that was – from that experience I went on to go to get a GED and then to go on to college and, ah, to have seventeen years of health and wellness and then

again, because, you see, I was a woman with multiple vulnerabilities and no matter what I was doing, there was always issues looming of the mental illness and from time to time I would have breaks and go in and out of private hospitals for medical issues for a few days. But I never had a really major, really major break and I had a husband who protected both me and the children. But then in my forties – which is at the end of this cycle which we're talking about – ah, I ran into a serial rapist, or he ran into me and he, he – there's newspaper articles about this. About how he, you know, terrorized this little town that I lived in right outside of New York City and how many women, but for those women, I'm sure that was a horrible terrorizing experience but for me with my background, it really caused me to split wide open and I had a terrible, terrible, ah, time and I, I, ah, couldn't get myself back together. I lost my job and finally I got a – friends of mine came to rescue me and send me upstate New York to a new job which they thought, "Oh, you'll just get a new job and you'll get over it." But my children and my husband were not with me and the place that I went to was very white, very isolated, very secretive and had it's own issues. So there I had a major, major mental health break and that's when I ended up in Washington, D.C. living on the streets and went to the mental hospitals. When I got over that experience – when I got well from that was about seven years later and I went back to work in my chosen field and was doing fine but I kept having this looming feeling that something wasn't right and I realized that it was even though I was working and working with women like myself, I was living in fear – still living in fear. One of the things Lisa had taught me was don't, don't live in fear. If fear is a part of what you're doing, if discomfort is a part of what you're doing, you're not doing the right thing. So, I decided that I would join the Consumer Movement where I would act myself. If I acted myself, I didn't have to worry about anybody else outing me and I joined the Consumer Movement – came to Philadelphia to work in what for me looked like to be the biggest consumer movement in the country. I wasn't in the Consumer Movement in New York at all and wouldn't have been comfortable since I had all these professional experiences in New York being in the movement. Came to Philadelphia. Worked as the first – worked as the Director of the first consumer operating service program. A case management unit. All the people in the unit were people who were consumers of mental health. All of them were people of color. It was part of a research demonstration funded by SAMHSA and we were the keepers, the protectors, the case managers, the, ah, the people who filled in the gaps of the lives of some fifty-four people who were people who were the last people to leave the mental hospitals when they were closing them down in Pennsylvania and our job was to make sure that these people got whatever they needed in their community settings. Wonderful program. Wonderful opportunity and turned me into a consumer advocate to begin to understand – went to my first alternatives. That was my first

consumer advocacy experience. It was really truly a life changing – again, another life changing experience.

Q. When you say alternatives – that's the Alternative Conference –

A. Yes.

Q. and that's the conference where consumers get together and share ideas and present programs.

A. Right.

Q. When you said – just to backtrack – when you said that you, um, decided to get into the Consumer Movement -

A. Ah huh.

Q. how did that come about? I mean, what was the first thing you did?

A. Okay. I decided that I wasn't going to – I was living in fear. I was working. Great job. I always had great jobs by the way, you know. Unlike many consumers who never could finish school, who never got a chance to work, I've had wonderful work experiences. I just could never keep them because of my disorders. I could never keep them, but I could get them. So, I was watching TV in New Jersey and New Jersey shows a Philadelphia station. I was living in New Jersey and watching TV and every winter for like three years, maybe two years at least, I saw a project in Philadelphia called Project Share where these men and women were going out and getting homeless people to come in off the streets. These were people who had lived on the streets themselves. These were people who understood why people stay on the streets. Who could talk the language of the people who decided that they were already dead. What difference did it make where they lived since they were truly, as far as they were concerned in their own existence, people who had died. And so, um, of course, that's my framework. That's the way I felt when I was homeless, so that's why I frame it like that and I watched that. It stayed with me for one year and maybe I saw it again the second year and I – and all the time I had this other thing that was coming on me. I'm very afraid working professionally in this world because someone who may have seen me in some of those times when I was homeless and sick and or both, may come here and say that and then I could lose my job. So why am I here. Lisa taught me don't be where you're scared. So the two came together one, one day and I said if those people can do that, maybe there's other things they do there. Maybe there's other things that they do with consumers besides that that I could do. I have skills. I have a

background. So I went. I called them on the phone. Got their number from the phone book which wasn't easy cause Project Share wasn't listed as Project Share. It was listed under the sponsor's name. Project Share was made up of about eight to ten little consumer projects that all had been put together under this one umbrella and they were providing peer support services for consumers. The Case Management Program was the only fully funded SAMHSA research program. It was big money and big time. And, ah, when I called and I said who I was – the woman who interviewed me asked me about, you know, my background – she said, "You know, we have just – we have something open," which is the way my life always was though. When I was ready, it was there. You build it, I would come. (laugh, laugh) So, she said, "Well, I'm going to make an appointment for you and come on," and I did and I met Paolo DelVeccio who was going to be my supervisor. I went upstairs and met the other actors in the game and I was practically hired that day. They couldn't believe that I had the background that I had and I was also a consumer of services and that I wanted to come out. Basically that's what I was doing. I was looking for a place to come out where other people were out. I didn't want to be out where nobody else was out. I didn't want that responsibility or I was living in fear of it. So, that's how I got the job. It was really fate.

Q. It sounds like it was tailor made for you.

A. It was tailor made. I mean, this job required someone who had some professional skills.

Q. And you said SAMHSA earlier – I'm sorry, you just changed the name.

TAPE 1, SIDE 2

You mentioned that the project was funded by SAMHSA. I'm not sure what – I know it's an acronym but I'm not sure –

It's an acronym and I was trying to think – I'm so awful – when I'm in these stories I can't get out to get these things. They have to come out where I am and go through another part of my brain. But I know it had something to do with the – I think it's Services Administration Mental Health or something like that. I know MHSA is Mental Health Services Administration. Oh, that's it. Substance Abuse and Mental Health Services Administration.

Oh, okay. And that's through the Center for Mental Health Services.

Yup. Actually, the Center for Mental Health Services is under SAMHSA.

Okay.

And SAMHSA is under the large what we used to call NIMH but it's no longer called NIMH. It's called NIH.

National Institute of Health.

Yeah. So then it's that. It goes down. There's a whole hierarchy. But SAMHSA is the mental health piece. The substance abuse and mental health piece and that's the piece that was in those days they had a, a, a community support component that was just beginning to acknowledge because it really supported consumer work – peer support. Support as a consumer clubhouses. Consumer was beginning to support consumer voice. Had some very creative, innovative leadership from the Federal government, from the people that ran it and saw consumers – the possibilities that we live with today as consumers where we're all over the place, they had envisioned that back then and were beginning to address that and invite consumers in and taking a look at what happened when consumers did run things and when consumers were invited in. Just looking at the early participation and encouraging consumers to come out and join the partnership for various endeavors. Minimal – what I was doing with that case management project was probably the most sophisticated and the most threatening piece that they had ever done because on the other side of what I was doing with this unit of six people and these fifty-four, ah, people who were continuing to – who were still mental patients. They were not ex mental patients. They were still mental patients. On the other side there was a professional group very, very much just like the group that I – all professionals working with the other half of that clientele and the research proves – and the research exists. It's documental. You can read it anywhere, ah, and the research proved that there was no difference between the work we do and the work they did. That doesn't sound amazing to the general public except if you're talking about crazy people taking care of crazy people and they are not only not getting any crazier they're getting well. Unbelievable!

Do you think that if you had been given more leeway because I imagine you had to work under certain procedures –

Definitely. Definitely rigid.

You could have even exceeded the success –

No. Because success in those days depended on the environment and there was no supportive environment. I think – I think we pushed the cookie way further than they ever dreamed. I mean, one of the – I remember one

thing that we did. One of the – there were no Hispanics in the – in my unit but yet many of the people we worked with who were these last vestiges of the people – chronically mentally ill people – they were Hispanic and I said, “Why didn’t you all hire a Hispanic when you were putting this unit together?” Because the unit was together when I got there. I mean, I didn’t make it African-American. There was the – the Unit Coordinator was Hispanic but she didn’t do much going out into the street. She was the one who did the paperwork and worked with the Feds to keep all the paper pushed and did all the time sheets. She was an integral part of the project. But she was not into the case management. She was considered a coordinator and she was Hispanic. So, we used her a lot for interpretation. But I wanted a worker. A street person. I wanted one, a Hispanic. We couldn’t find one. So I went to the mental hospitals. Found a man that had been in the service. Had an enormous background but had this terrible, terrible breakdown and he was – they were getting ready to, to, to – what’s – release him (laugh, laugh). They don’t use release. They were getting ready to release him and, ah, they were thinking about leasing him somewhere in the upper part of the State and I talked with him and talked with him and talked with various workers about him and was able to get him released from the hospital to come to work in the unit. Which I thought was a coup and he was fabulous. He was fabulous. He had lots and lots of leadership in the service. He had been some sort of staff sergeant so he had all the things it took and what he didn’t have was a place to go to be somebody. He had a place. He could have gone to a clubhouse up-State but no place to be somebody and he took to that job like a duck to water. That was always really clear that part of being well had to do with being recognized as you were – the cultural piece – and being accepted and encouraged. So, spoken to in your own language. Understanding the way your culture looked at what was going on with you. All those were critical components to wellness and mental health that had never been addressed and it’s still difficult to get the world to address them. But there in 1989 and ’90 we addressed them. And that was really part of what, what our success was. We were the same as that. In fact, we were no different between us and them. I remember, we used to bring some of the people into the office because, of course, mental patients never get invited to meetings. You always go to the hospital and hope the doors are locked. So, I would bring them into the office downtown Philadelphia. We were in this meeting and I was having a bad day and I was going on and on and on about whatever was wrong and one of the people who we were still calling patients in those days although they were consumers just like us said, “Oh, Jacki, get off of it,” and I laughed until I – and I never did that again. The point is I always said we were the same but, you know, I hadn’t seen them accept that. But when she said, “Oh, Jack, get off it,” remember I’m the director and she said – and I said, “We did our work.” That’s the day I knew. So talk about best moment was the

day that this woman who was considered so clerically mentally ill she couldn't be placed in the community or she had to be placed in certain kinds of settings with lots and lots of support – she said, “Oh, Jacki, get off of it.” Come off of it or get off of it. She made my world, you know. Yeah.

You also worked – now that was Project Share.

That was Project Share.

And that was –

Research and it ended.

And you then to a training sponsored by the Americans With Disabilities Act.

Yes, ah huh.

Can you tell me about that?

Well, let me just say one more thing about that. That project set the tone so that here in Philadelphia they continued to have peer support programs that are paid for out of Medicare or Medicaid dollars – I'm not sure, but the one that pays for services – pays for peer support out of Medicaid dollars because of the work we did. So we broke the barrier in many ways. But that is a major systems break through to have and I'm really praying that some day we'll have trauma services paid for in the same way for public mental health.

So that was the first –

The first.

Very first program.

Very first to ever be paid for by the system in the mental health, you know, peer support – paid for.

So, any, any peer run program running today, ah – can be traced –

Has the possibility, yeah, there are not a lot of them still that are paid for by those particular dollars. The hardest dollar to get is the on-going system's dollar which is either – I think it's Medicare – I'm really confused about those two words when I use them but it's the one that pays for mental health services. That program sets the tone in dollars and now many other programs now are working out ways to get it. Cause you have to do it

through the State system and the, you know. But that program did it and it's now currently being funded in the same way. It still goes on and it was the benchmark, the pace shaper. I'm very proud of that. Big moment. Big, big moment when that happened. And that's what makes me think that peer support can some day have that same relationship to the Federal dollars. That's what it means to the State. It means that the State doesn't have to pay for that service that is eligible for Federal funding which comes from – Federal funding comes in the form of Medicare or is it

–
Medicaid.

Okay, Medicaid. I mean, that is phenomenal. Of course, you don't see that written up because they don't want to encourage, but I'm going to be the voice for that as soon as I get time (laugh, laugh). That's my new project. That's where I'm going. I want trauma to be paid for with those dollars and I'll do a break through program if I have to but I'd love to see the system address it.

Do you think that after – I mean, after spending what, fifteen years since –

Ah huh. Ah huh.

- is there enough progress in your opinion.

Already. That's the secret. The secret is that I'm ready and that I understand and that is what it really takes. It really takes someone who understands who has the – who can – who has the evidence that it worked and that can ferret the out different components and then build sort of a coalition around it and I have the ability to do all of those things, you know. I do. And since I would – I hope some day before I was ready to retire that might be my last swan song. It might take me four or five years to do that which would just about come out right for me. I'd like to retire at seventy-five.

Think you could?

I don't know. We'll see. (laugh, laugh) I don't know. I'd like to do something different.

You're just so active. I can't imagine you ever –

Well, maybe somebody can teach me how to write and I could do my memoirs in a way that I want to.

I think you, you're – all you need is a tape recorder.

Yeah, that I got. I got that.

And have someone transcribe it.

I'm really good at that.

You're very eloquent. That's all you need and an editor.

That's right. We'll see. (laugh, laugh) But don't, but you remember as you go around the world saying you find someone who has the money to help you do that and I'll be okay. I'll be – but I'm not ready yet. (laugh). I'm not ready. I want to do this piece first.

So, can we talk about the advocacy training that was sponsored by the –

Yeah, the ADA. Just about that time in the early nineties, the ADA which is when the American Disabilities Act was passed. I don't know the specific dates but I'll look them up and I'll get them for you and the ADA gave this money to a disability group called DREDF and I don't know what those – that acronym stands for, but I know its DREDF or something like that and they gave this wonderful cross disability group – it was mostly run by women, at least the leadership was – lots of women was in the leadership of this disability group. And they gave them money – excuse me, I don't know where these five hundreds – the government is good on five hundreds – to recruit five hundred people from across the country – cross disability. Every disability that I've ever thought of or heard of all the way from sensitivity to carpets and, ah, things in the what – environment. People who couldn't come out of the house because they were sensitive to the environment outside and people who had to stay in rooms because they were sensitive to the environment inside. Those people were at the meeting all the way to people who were publicly trans – publicly, who were multi – who were diagnosed multiple personalities who actually brought a number of the personalities to the various meetings and operated from those personalities in those meetings. I mean, it was – for me, it was heaven. I've never seen anything like it before and I don't have to ever see it again to ever remember. It was – every moment of it was as sweetest as honey to see all of these people – people that couldn't walk, talk – contributing to this movement. They could write or they had some way of communicating with their fingers to tap out and many, many of the people were disabled in different ways. So differently disabled that they had to have people with them to do fifty to sixty percent – in some cases ninety percent of their mobility depended on. And all the leadership was people with some sort of disabilities – blind people, people who people

used to laugh at because they were different sizes, you know. I'm telling you for a person with a disability, it was heaven. Until I went to that training – I did the first training with about twenty days all in all – to do this cross training. To understand ourselves and how we related to it and how we were to be trainers and how we were to be spoke persons in our communities for this new act that had been written that was going to talk about the rights of people with disabilities. Then they had a hundred people that they chose out to do specific projects and I teamed up with an African-American woman who was – who used a wheelchair for mobility and she and I started a, a – well, we started a project and we gave it our own name and I can't even remember the acronyms but I'm going to get that for you, too. So, any how, we started this training group and we put together our own curriculum and we went around New Jersey. We trained something – I think it was one thousand two hundred people, one thousand six hundred people – trained all kinds of – we went in all the health related areas primarily. All the little groups – the national association or the local association for this and we did – we did everything we found in the phone book. We went and we trained them about the Americans With Disabilities Act and allowed them to show us how they would interpret that for their particular population. And, ah, we submitted that all back to the government and we got certification for that and commendations for that. So that was my cross-disability and then I came back to the consumer movement. After all that work, I was really trying to get over to the cross disability. But the consumer movement called me back. Ah, because I no longer worked in Philadelphia so I didn't have a job so to speak. When I was in Philadelphia, I had a job but that research project ended. But I was really bitter about that. I was bitter about the way it ended and even though the county picked it up, there was just so much about it that I didn't enjoy – the way it ended. The way the people – the way the workers didn't get support for the ending. It was a very scary thing for me the way research projects recruit people – whether they're consumers or just professionals or people without a lot of training and then at the end of the time they just drop them. That was a big – again, wherever trauma was, I would always react. And I reacted very badly or in a big way. I had a huge response to it. I had a huge response to this project ending and, ah, after I did the disability piece, I guess I kind of calmed down. I did that two or three years and I came back to the consumer movement because there was a group of women lead by again a SAMSHA leader and a woman who worked in Massachusetts – mostly with people who had developed mental disabilities and who had, um, ah, had – um, who were born – I can't think of the name they used for it. I know we used to call it mental retardation. But they don't call it that any more.

Developmental disabilities.

Developmental disabilities. I guess that's what it was. She was a specialist in that and she used to – and so these two women got together and started looking at mental health and thinking that they really ought to, um, do something about what they were talking about women who seemed that people that – these women did a lot of drugging, a lot of drinking and seemed to have a lot of mental health issues and it seemed as if all this stuff had some, some common bond and what they were calling it was they thought of it as trauma. And they thought that maybe early childhood sexual abuse or violence in women's lives was a precursor to mental health diagnosis – not to the issues, but to the diagnosis – to the, the very diagnosis that may or may not be really mental health – may be trauma and that these women – the drinking and the alcohol and the drugs was a form of self medication in response to that early childhood break. And they created this conference called Dead Vision. And they brought together policy makers and psychiatrists and social workers and readers and writers and we all came together to do this huge conference. I didn't have a name for my, my – for the things that were wrong with me at that point. Even with Lisa all those years, we never called it trauma. We didn't name it. We just dealt with who I was and how I was broken. But – they named it trauma. It was the first time I ever heard the name in that relationship. Maybe I was a person who had been traumatized and continued to be traumatized all of my life and that's why my life had been such a series of problems and I learned at that conference the way that you could tell that a person like me – the way you might as a lay person identify us, was no matter what happened, we would never get better. We would have good times. We'd have bad times, but it was a constant revolving pattern of never being well long or never being well enough. It was always you never got all the way out of the bubble. So, if you have a person in your life in your family saying, "She never gets better," or "Or her treatment never helps her or nothing works for her," or "She doesn't stay long enough," or "She can't seem to get it." When you hear people having that kind of conversation, you can bet your life it's one of us – a traumatized person. And when I first went to that conference, I thought it was only women cause we all have learned that there are women and there are men and this new, whole big piece about the priest and the sexual abuse just only confirms everything we've always known about women and now it tells us it's not about women. It's about children and that if you are in any way a violator of children, that the children will have some response for ever. That's just a reality. We didn't know that that day at that meeting and I went to that meeting and again, just like the ADA where I saw every disability represented – at this conference I saw women and their fears really acted out in every way it could be acted out and I went there to talk about my job experience because they wanted to talk to a consumer. They wanted a consumer who had had a job and the job had

not turned out well and who wanted to talk about that as the impact of that job experience on trauma or on the, you know, how work and this, this configuration fit together and I went up there to talk about that and low and behold I talked about my childhood and what had happened to me. What my life was like. No plans. Didn't have any idea on earth that that's what I was going to talk about. I think it was more than just happening. It was probably waiting. It was like an accident. It was the accident that was waiting to happen. I had never had the opportunity and there it came and I was as shocked as everybody else was. They were going "Ah," (laugh, laugh) because it was a terrible story of violation after violation, treatment failure after treatment failure. Family sort of disowning me and abandoning me after, you know, just, just a life of turmoil.

Trauma or topa-trauma

Trauma or topa-trauma, right. I didn't have those words then so that's why I didn't use them. But that's what it was.

When you first heard what was defined – or at least you had words to use, how did that impact the way you felt about it – the way you communicated?

I talked to myself for the next four years about that word. I loved it. I adored it. It was defining and I was helping to define it. It became – the word itself, at first, was the fuel because I had nothing else. But at least I had a name. I had a name for the game. I had a name for what I lived. It was the most – I had so many life confirming moments but it was a big one. There was a big – just to have a name and know that it wasn't what was wrong with me. It was what had happened to me, you know. I began to coin that and to go to place to place and say to people if you could just stop asking people what's wrong with them and just asked them what happened to you, you will change the outcome because you'll help people to think of themselves as a person that could look at something rather than just be the victim of something, you know. To have this, this nebulous thing that comes down on you. Well, let's look. Maybe there's a precursor. Maybe there's a root cause and maybe some of it is – comes from your family and maybe some of it comes – but maybe some of it comes from a place where you can take control of, cause that's the secret. It's not just in naming it. It's then being able to believe that you can take control of it. You can have something to do with how it affects you from this day forward. What a relief. What a revelation. So that's what happened at Dare Division for me and then I went home and for two years I was under the bed so devastated by that experience – so frightened out of my mind at the possibility, the possibility of being well was so scary that it set me back, almost back to my early days. Now, I wasn't sick acting out. I just

couldn't come out of the house – pulled down the shades, threw out the phones and I lived in almost total isolation for a year.

Why were you afraid?

Trauma. That's the way the trauma took – you see, if you could think of the trauma as something that has been there for ever and that in some way you have developed – you have used it to cover all things that you don't want to do. So something gets really scary up in your face where you would think oh, I'll embrace – it would say no – scared to be well. Scared to take that kind of risk. I'm functioning. I'm eating. I'm sleeping. I'm getting dressed. I don't want to go. Maybe I'll fail. Maybe this is just a sneaky way to get me back out in the street living on the corners again. Your mind is a terrible thing and when it's been allowed to have nothing but negative thoughts, it's not always your best friend. So, for two years I was under the covers and under the bed and not able to function.

What finally brought you out of it?

This, again – I got these weirdest stories – I got two stories that I want to talk about at that time. I want to talk about – I began to, one of my sons came to stay with me during that period. So, he and I were in the house alone and he had a drug and alcohol problem. A really bad one and he was seeking, trying to get some services or some advocate was trying to get him into a program up in Binghamton, you know. Binghamton was considered a drug free community. You could send people up there – Binghamton, New York.

Yeah.

They wanted to send him up to Binghamton, New York and he – you know, people with these kinds of issues come in and out. They'll come knock on your door and then they'll disappear. So he was on the run. He came and he went and then he disappeared. They were looking for him. They came in and knocked on my door looking for him and, of course, I wasn't going to the door but they put the, the stuff under the door and they said, "We found a doctor for you." And they had the name and the telephone number of this doctor and they said, ah, and, you know, he's interested in – whatever this note said, here's the doctor, here's his name. So my son when he did come back – it was three weeks later – maybe it was a month later, I don't know, but he did come back to the house and he said – and I told him that this note had come and he read it and I guess at that point he was on – one of those days – now, we didn't have a phone so they couldn't call us. We didn't have a phone. So he went out and made the call to the doctor and probably by the time the doctor got there, he was

gone again. The doctor came and knocked on the door and began to talk to me through the door. Eventually, the doctor found my son home and my son let him in and this doctor came in and he talked to my son and then the next time he came – I don't know whether he talked to me through the door or I let him in or whether – I'm not sure, but he began to talk to me about my son and little by little he began to talk to me and he kept coming. And he became the person who began to talk to me about why I was in the house. He said things like look you certainly seem to know a lot about the world and about your son's addiction. You have a great understanding about addictions. Why are you in the house? And little by little he talked me into – he never said he was going to be my doctor. Those words never happened. My son went up – the people found my son and – whatever, found him in the right mood and got him up to Binghamton so there was just me. I started opening up the door for him. Something I never did for anybody. He talked me into getting a phone so he could call me. I got a phone. You know, he began to help me put these little pieces together but they were slow. Well, it was two years, at least two years and finally he said, "These people from this group from Dare Division said" ah, they sent me mail. I didn't open my mail in those days. I had this – that's part of the trauma experience. Part of the fear is you don't want to know, so you don't open the mail. You don't open anything new, you know what I mean. Part of being really, truly traumatized is you don't want to know. You don't need nothing new so mail was a problem. And I met another woman who hadn't opened her mail for five years. I felt so much better. So anyhow, he said to me the mail came and he would talk to me about the mail. He said, oh no. The phone rang. That's what happened. The phone rang when he was there one day and I said I'm not answering the phone. He said, "Just when I'm here. You don't have to answer the phone any other time. Why don't we start with you just answering the phone when I'm here. I'm here to make sure that if it's bad, you know, I'll help you." Because what I was trying to do in those days was to get disability. To get a form of disability payment for my condition. And he said, "Suppose the disability people want to talk to you. Then if they call when I'm here then I can talk to them." And he just sort of worked me into answering the phone and I answered the phone and it was the women from Dare Division. They said, "We're starting a technical expert group and we'd like you to come." Well, I couldn't tell them that I didn't come out of the house cause I could talk fine as long as nothing was threatening me but if it started to threaten me then I got very silent. Can you imagine me silent, Steve? You'd know something was wrong (laugh). So, he talked me into answering them and he got on the phone and he talked to them and he said what would I have to do. Well they said I'd have to get on a plane and I'd have to come to Washington, Virginia and I'd have to spend the night and, ah, a couple of other things, so he said, "Can she take a train instead and can somebody

come with her," and stuff like that. He set it up and then he had another patient – another person he was seeing – he didn't call us patients. He had a name that was – he was from Africa. He was African. He was an African man and he understood trauma. He told me the story about his tribe. In his tribe you were not allowed to go to school. His father did not allow anybody – his father was the king or prince or whatever and didn't allow anybody in the tribe to go to school and the missionaries came and set up a school and he said, "If anybody in this tribe goes to school, it will be at the point of death. I will kill them before I will let that white man's poison come into my world." And so he was sneaking away and going to school and one day he looked up and his father was coming at him with a bayonet and all the men coming and his father was trying to kill him and he ran and the missionaries took him and took him away and brought him to America. So he understood trauma. His father was going to kill him. So, of course, he's a PHD and he's a learned man and he loves the idea of the broken spirit and he has all kinds of little stories of his own. But, of course, I would need him, you know. But another thing he did – he was a drug and alcohol specialist. What he was doing with me – that was not his specialty – that was just an interest. He found this work –

TAPE 2, SIDE 1

a way to do it, so working with me was a way for him to learn more about this piece because he had it. He had trauma really bad. He had another patient who had been a police woman who had done drugs on the job and been found out, discovered, whatever it is, caught, caught and she was fired from her job and ordered by the courts – instead of jail she had to go live in a rehab and she couldn't live in a – she couldn't go to a big fancy one in Phoenix, she had to go to a community based, oh my God, you know, twelve women in a house for four. (Space in tape). Wonderful to get over it. So she was – so he – so she had lived through the experience and now it was time for her to leave there and go back home to her husband and her kids and he was to be her doctor. He was her bridge and he thought that she might be the perfect person to join with me for me to begin those first steps out of the house since my fear seemed to be that something would happen to me. This is a cop. I mean a person who is a woman, which I had to have, that took away the possibility that she would violate me and then she didn't have a gun but she had all of the strength, all of the power, you know, to act out those behaviors and act like one if she needed to and, ah, she had just been through a very humiliating sort of life changing experience of her own and he thought that it would be a perfect match that the two of us could probably be good for one another. And so he set her up to be my escort to these meetings and I traveled with her. Some times she'd drive me – I think

the first two. She's an excellent driver which most police people are. They have to drive all those high speed things. So she drove me a few times. She made all the hotel arrangements. She did everything. She got my food. She did everything for me and she took me to the first two or three meetings in the car and then we got to the bus – I mean to the train, and then we finally got on a plane she and I. And for at least a year – maybe a little more, maybe eighteen months – she was my escort and she would come here a couple of days a week and spend time with me. We would work on whatever it was that we did at the meeting. She was not a full time employee or anything like that but she had this one job and she did it and that was her – that's what he got her to do as a volunteer so she could write down that she was working. She had a volunteer experience that was enriching – that was helpful to someone. You know, he did all that writing part. And that's how I got back out of the house and got to go to Dare – got to go to the technical expert's group meeting. And some of those meetings were so overwhelming that I don't remember a word of them. And others are – I would be okay. I didn't know the women. I couldn't remember their names for at least three meetings. But I was very taken by a couple of women there and it turned out to be the two critical women – the woman from SAMSHA whose name was Susan Salison who was really a leader in women's health and mental health issues in SAMSHA and this woman named Rene Anderson who was the woman who had worked with the developmentally disabled. Was a trauma survivor herself but also a professional. So these are the women who became more or less my mentors and at the end of working maybe three years that group met and then at the end of that grant – by the end of that grant, there had been enough meetings and enough white papers to go to the next step which was to develop the document that was then put out for public response to recruit people to be a part of the Women in Violence and Co-Occurring Disorders Study. And I went with the Study by that time.

And when you say "co-occurrence" because I don't think we used that –

That's what they used. The term – we used to call it in the old days, oh, I don't even remember what we used to call it. I remember yesterday – today I can't –

Dual diagnosis.

Dual diagnosis is what it used to be called. They called it co-occurring because it happened at the same time and while you may have been dual diagnosis that didn't describe the action of the disease. It was the connection of all of it being together that was so critical and that's why dual diagnosis is not

a misnomer, it's just that it doesn't describe the action. It describes somebody else outside doing it, but what's going on with the woman is the co-occurring and they wanted to make it more personal because trauma is personal. Trauma is not a diagnosis. Trauma is a personal affect and so putting them together they wanted names that went with that. So I was part of writing that – not with a pencil but with this talking about the experiences that I had. Talking about what I thought would be important to these women. If we were going to study with them, what parts of them, and the biggest piece I brought to that study was do not study the women without studying their children because my children lived lives of hell because I lived a life of hell. And my children ended up in all kinds of institutions and all kinds of situations and continued to do that because of what I lived through. That my apples – they didn't not only fall far from the tree, they didn't fall off the tree, you know. And that was a very important piece that I brought to that research – to that idea. And now in the study we are definitely studying the women and their children and hopefully that's what we're going to continue to do.

And this research is still going on?

Oh, yes. It's going on. It's, it's being run out of a, ah, research institute in Albany called Policy Research Associates and, ah, PRA – Policy Research Associates. Hold a second. Hold a second. The women – Co-Occurring Disorder & Violence Study. And as a part of that work between the technical assistance group and the women in violence study, I began to be a national spokes person for the issue of trauma. By telling my own personal story, I've been able to get people to understand who the women are. What kinds of issues they may have addressed and some recommendations to the audience about looking at the public mental health system as the place of first resort rather than that it cannot accommodate these women looking at accommodating these women and their children in the public health system so that these women do not end up being re-traumatized. And one of the out growths of that was to develop a policy against seclusion and restraint. That was one of the first pieces that came out of that. One of the second pieces that came out of that was the knowledge if you don't treat the children when you're treating the mother – if you don't acknowledge the children, then you're creating the second generation of the same issue. The third was that battered women, women in prison and men also had lots and lots of this population within their recurring recidivism rates of people. All of those. So women who constantly we would say keep marrying Bill (laugh). That woman is a traumatized woman and that's why she keeps marrying Bill – looking different, coming from a different background, different race – but it's Bill, you know. We knew it happened but we made fun of it. We didn't understand it as why the people in prison – many, many women in prison

go to prison because of their illness – because of their behavior that they cannot modify or when they're in prison, they stay longer because they can't follow the rules because their fears can be so great that there's a certain key and when that key turns, it just sends them off. There are certain dates and times in their lives when they're going to go off. So all of this stuff was never talked about before – never acknowledged. Never looked at. And finally we came to the conclusion, the reality, that many men were abused. This is before the priest stories because – and that we needed to include them in our constituency – but different because the first thing we found out when we went to treat men is for men you have to first help them to identify their emotions. You can walk up to a women and say, "I want to talk to you about your feelings," on the way to identifying the person. You can't do that with a man. You have to first put him in a position where he can identify that he has them himself. And once he gets comfortable with that, then you can move through that. So, new information. All this is new knowledge. So happy to be a part of it. So, I began to be a national speaker for that and I began to work on different kinds of people – things people were writing about mental health and mental illness, you know. Began to do some work like that. Now I'm quoted in a lot of little books, newspaper articles, little – most of the SAMSHA newsletter and related things, you know, have something about me somewhere. But the most important thing for me, besides trauma, was the recognition that people of color needed to be recognized and that culture counted in the mental – in the road to recovery for mental health, culture counted. That's it. So some time in that early time before this study – so it may have been 1992, 1993, '94, I became a part of something called the National Consumer Survivor Social Policy & Research Work Group. Met some fantastic people who were part of that group – Jean Campbell, Ray Unzicker, Darby Penney – just some people that – women particularly – Pablo DelVeccio by that time he had left Philadelphia and he was working on a national level. Laura VanTosh who worked the first grant that I worked on – that research grant in Philadelphia. She was on it. So some really good people were on this, ah, social policy work group and their intent was to say that, although consumers had been included by the Federal government for a long time then, it was mostly at the clubhouse level. It was mostly at the peer support. Sitting with people in the smoking room, you know. Hearing their stories and sort of being a pal. That there were other things that needed to be affected by our work and that we needed to get on with that business and so the words "social policy and research work group." We wanted in. We wanted to be at the making of the policy and we wanted to be part of defining what the research would be and why it would be and what you could do. We wanted to make sure it was useful to us. So, in that group I took on a whole different world. Now I'm taking on the research world. That trauma over here. Got this peer support thing. Now I'm over here

messing with the real people and this is really scary because that was very hard and took a long, long time and the battle isn't won yet.

I imagine there was a lot of resentment from the researchers –

Tremendous resentment.

You're walking on their turf.

Well mostly it was – they weren't even used to being questioned. It wasn't that we were attacking them. They didn't even like being questioned because they had never been. They weren't questioned by each other. Although – we didn't know then that researchers came from all kinds of different backgrounds and came to the table with all kinds of different ways of looking at things based on whether you, you studied from one point of view or another – based on the doctrine, you know, or the, the guild you belonged to or trained in – whether you're a psychologist or a psychiatrist or sociologist or anthropologist. All of those things had something to do with how you interpreted your findings. The one thing they had a lock was how you do the numbers, you know. That game was theirs. We wanted to talk about why you want to do it and why you want to do it with us and what's the gain in it for us. And where was nothing about us without us – was the power. We entered the research field. You're not going to do this without us and you're not going to write about us without us throwing your work in the garbage if you don't come our way. And SAMSHA sort of supported it – slowly at first and now pushes it, you know. And stigma, of course, kept raising its ugly head and alternatives. So, I'm going to alternatives and I'm having the time of my life because I've never – since ADA I hadn't seen a group of people who shared these common barriers with me. But I was not there as a woman of color. I mean, there was no recognition on the agenda that there were people of color in this movement. There was no recognition there were women in this movement. This was purely us consumers and we were all of us were assumed to be white males because that's who led it. And that was fine. Just to be there in that crowd talking about our own issues and how things were affected. But there was no she and no woman – none of that was on the agenda. Nothing about that framework was addressing issues. That's how I began to talk about that. It didn't make me popular in the consumer movement because – but in this social policy research work group, I asked them if while we – while we were working to get into the research, could we also ask them to do – give us some money to look at something about people of color. Specifically I wanted to look at people of – consumers who were people of color and see if we could like maybe write about their point of view. You know, just get a little something on the record. Well, it turned out to be the only little something that actually was done and what

happened is they got money. They gave it to the National Empowerment Center and they hired a white guy to write - oh, I couldn't believe it.

You're kidding.

So, when he called me my first response to him was well, what the "H" is a white guy doing with the money? He says, "Well, you know, I work up here in Massachusetts and my wife is part of the professional world in this area and, um, my wife is not a woman. She's a woman of color and, ah, I'm very sensitive to these issues. I've been talking about them up here and I didn't have a job and so, I'm a writer, you know, and a social worker and they thought I would be a great candidate." I said, "Everything is great except you're a white guy." You know, you're a white guy. How are you going to write about white guys owning it and not letting us in and you're white guys. Oh, we had a bit to do so he says, "Well, I'm going to call you back and try to talk you into doing. I got the money to do. I'll call you back and tell you." Cause my whole thing. I was just incensed that after working with this group for more than a year, a year and a half, that they gave the money to this white guy. I just - I mean, the group was responsible for this as far as I was concerned.

Now was this -

It was called the Diversity Report.

Was it specifically for women of color.

No.

Oh, just people of color.

The group?

So you would have been satisfied with a black man in that -

Oh, yeah. I would have been - anything - I would have been satisfied with a Hispanic person. I didn't want it to be a white person. You understand? I needed someone who - that's why he was saying to me - well, my wife is a woman of color so my children are children of color. He did have some of the dynamics but not the ones I thought were outstanding. He was a consumer, you see. So what he said to me was I know you're angry but I think if you let me call you back, I talk to you more about what I want from you. I said, "You can call me back. I just want you to know that I think it's really an insult that I worked for a year and a half to get this money and they" - Jean Campbell and Ray and them, they got their money to go do

whatever they said they were going to do. I wasn't even in the room when they got the money, so I don't know what they were going to do with it, but they wrote some reports which I never saw. I don't even know what happened. There was one product that I do know happened and that was this guy, Ken Schloser, wrote something called "The Diversity Report," and he wrote it and he presented it at NARPA and he might have presented it the year you were there. And he came and he presented it and he talked about, you know, how he learned that his role as a writer was okay but that he should not have been in that role and he talked about his relationship with me. And in that report he addresses maybe six to eight people of color about the consumer movement. Have you seen it?

This sounds really familiar.

Yes, so you've seen it. Okay. So, ah, he wrote that and he interviewed us and then he sort of intertwined the stories with his, you know, his theories and it turned out to be a fairly good report. But in that report I make a statement – and you can backtrack this with the National Empowerment Center, you can go to Ken Schloser himself – I make a statement that the consumer movement is run by three white men and how can we have a movement with – how do we change that? And because that statement was in there, they refused to print it and for five years it sat on someone's desk and they talked to me every year at least once a year – they tried to talk to me to take it out. I said absolutely not. I'll rot first. You print it or you leave it. So, I'll say it again. I'll never stop saying it. And one day I'll get a chance to print it no matter whether you like it or not. So, eventually they printed it. They printed it about – they printed it five years after I wrote it, Steve. I mean, after it was written, Steve. And that's why Ken came to NARFA to talk about – you know, how the Federal government will do that. You know, you can talk to them and talk to them and talk to them and talk to them – just recently this woman – I don't know how you say the words, but the lesbian, gay, transvestite – she got – she fought – this woman, I can't even remember her name right now. But this woman got the idea that there should be inclusion, another voice, that that – within this group there are people with mental illness that they should be included. So she fought the Federal government and besought them and got them to give her the money to write it. And then they didn't like it.

She was from Boston, I think.

That's right.

Yes.

They didn't like it so they wouldn't print it. But what she did, she negotiated with them and they gave it back to her and they wrote a disclaimer that, you know, none of it – just taking themselves totally out of the picture. She now has it and she can do whatever she wants to, but they're not printing it cause she wouldn't change it.

I saw her at another conference. I think it was at NARFA.

I think it was at NARFA. I think we all saw her at her NARFA. So, I'm just giving you an example of – hers was a little bit – her fight was a little bit tougher than mine because she was pretty much alone out there. I did have the whole group although the whole group was not saying don't print it. They were like – print it, Jacki. Print it. Just print it. I said I'll die first and if I die I'm putting it on my tombstone.

The truth hurts, doesn't it?

But it really hurt then. The people were really hurt by it. But how the government can make you hurt, you know. Anyhow, that's what happened with that piece but it just fueled me on and in the meantime while I'm looking at this and looking at how race and culture didn't count, one of the things that I said in that report that's really important is that treatment providers did not understand why I wanted to be an advocate. They encouraged me all the time not to strain myself. Not to excite myself. Not to push myself. And as a result they never gave credit to activism as a form of recovery that works. It is probably one of the most powerful components that you could ever find to hold onto as a piece of recovery. And they wouldn't recognize it, couldn't recognize it and refused to allow it. And I say that in that report. So, that's what I believe and that's why now in my current role I will go anywhere that there is a population – whether it's a recognized population of people with mental illness or a none recognized population, I will go there and talk about mental illness in America. Mental illness in our society. The unrecognized person with mental illness, with mental illness. I will talk about the plight of black Americans who cannot admit – who can't – when I get on the stage and make a presentation, ninety percent of the people who come and surround me will be white women and they will come up and they say, "Jacki, you told my story," and they'll be crying and they'll be hugging me. They'll be congratulating me. They'll be extolling me to keep on with my work. Way off in the corner there will be one or two black women and they'll wait until the whole crowd is gone and then they'll come over and say, "I'm a social worker. I went through all the things you went through and when I got to be a social worker I stay as quiet as I can because I know if I get in an argument with my supervisor, and it ever comes out about my record, I'll be fired. I'll never be believed. So, I can't join your movement. I can just, you know, wish you well and pray for you."

There are other issues to being black because the black community doesn't support you and then the system is just waiting for anything. So, that's why you don't see black all over the map and why it had to be an old woman who didn't have a job to be able to do this work. That's why I don't have colleges rushing to my support. But when I make a presentation in a, in an arena where there are young black women and they come up and they hug me. I've had women just break down in tears saying, "I just felt like you were my mother talking to me from the grave because she never got a chance to tell me that story." You know, it's just so emotional to them that somebody can do this because they can't. The world is not ready – not if they want to keep working.

Right.

That's the difference. So, Alternatives was the place. It's the place I go every year and I talk Alternatives – I'll talk to whoever is at Alternatives. I had a fairly good leadership role there for a number of years. Not right – not quite right now because they've been under a big threat – Alternatives to not being funded because the technical assistance centers that put it on – there are three technical assistance centers. Each one gets Alternatives every other year.

For the record. The conference occurs every year.

Yes. And then they – different ones of these technical assistance centers – the one in Philadelphia here, the one in Massachusetts and the one in Virginia, West Virginia – they each get to do Alternatives and they get to do it where they want to and they get to do it in their way. And – but, they've been under a threat because they weren't in the budget last year and they were put back in the budget just recently for one year. And there's a possibility that there won't be technical assistance centers for consumers any more because our current administration isn't quite sure whether that's what they want to do. And if that is true, then Alternatives may not exist so there has been sort of a discouragement to me to talk about them, to say negative things about them because they need to survive. What I was fighting for was a fourth technical assistance center. I was never fighting that they should be disbanded. So, it's one of those tenuous places where I have to be very careful that I'm not quoted as saying they're not useful.

Right.

At the same time I have to keep on talking about that they are not useful to me and to people like me. So, they've been working very hard at Alternatives to find new people of color. New people who come primarily with different

points of view, too. They've been smart enough to have the faces, but not the passion and not the fervor and not the information that I bring. So in some way my voice is sort of muted. But it doesn't really bother me to the extent that I feel that I'm not going to Alternatives. I'm still going to Alternatives and as long as there is an Alternatives, I'll be going no matter what they do. And I still, as I walk down those halls, I will have all of those friendly people coming up and being my friends and I go there for myself, too. So, the friends, you know, the new administration is just not being very – they're not clear. I went – I testified at the New Mental Health Commission. Do you know about that?

Yes.

I testified there. Testified there with two other national leaders of great esteem – Sally Zinman and Joe Rogers – which I don't consider myself a national leader at all. But because I was bringing the people of color perspective, you know, I was asked to come and also because I have been in trauma and children in trauma – all those are my responsibilities (laugh, laugh). But there's something they didn't ask me about and something I wanted to say to you. I think that besides the fact that African-American women have a difficult time coming out as consumers. If they are professionals, it is impossible but that's also true of many people in the world – that aren't of color. People that have jobs and many women and men go to school because they have this background in their family. So, many, many people in the social services and the human services go there because their parents were alcoholic, because their parents had these issues, because their lives were chaotic and they look for answers by going to school to learn about themselves. So, these practitioners really know, but there's a total discouragement in the system of having these practitioners identified. In some agencies they are told when they are hired you must not disclose if you have any of these issues in your background. And I wanted to say that.

So they were actually told that?

Absolutely and they have to sign the slip.

And what's the justification for that?

Well, because it doesn't give you enough of that, um, what's the word we use -

Oh, us and them?

Us and them. There's a distance that's required to be a professional. Sort of an objectivity that you lose if you get up all, in it, in it with people. What it is,

is they want to totally represent them and if you allow people to bring their own truths and their own reality to the table, then it's very difficult to follow the company rules if you're bringing your own truths and reality to the company table.

Right.

It's that piece you talked about when you were saying I imagine there were lots of rules. There weren't so much rules as barriers that were built in by having us act like people from the system rather than people like who we were, you know. There were things that they didn't want us to do because they didn't want us to be – there was only certain – there were barriers and only certain things they would allow us to do. Some things they wouldn't allow us to do that we thought were good. So, this goes on and on and on. So, you have many professionals who do know. Many people in America have some form of depression, have mothers who were mentally ill, have – I mean, on and on and on and on. This society is a crazy making society.

Yes.

So, we're every where. We can't come out because of our jobs are a threat – our livelihood is a threat - our personhood in our communities, our standings, are. And that's not just for African-Americans. It's worse for African-Americans because the African-American community needs to be educated but it's there for everybody. It's a problem. It's a real problem. And what that does is help people – people get meaner because they have to deal with their own stuff and when you're wrestling with your truths and their truths, then the personhood can't reach out and touch somebody. So, you're there and you're being very objective but you're having no emotion. So, you have to be emotionless and that doesn't help us. And that's why we want to do the work ourselves. People that are outed want to do the jobs that people who are not outed are now doing but feel that they have to stay in them and be non-objective. You want to be non-objective, get out the job. I want it. So, I'm willing to say that. Get out of the job. Go teach school or whatever it is you can do where you're helpful to the society. But I think you're a barrier when you know the truth and you still keep uttering the barriers because you change. Any time you live a lie, you change. You may think again, but you're changing. A lie will change you.

How can you help someone when you can't help yourself?

When you can't help yourself. You can't be true to your own self? Whew. I've been there. I mean, I know the difference it made when I walked out that

door and said never again will I sit in the office behind a desk and look across it to anybody. I'm either going to sit on the same side or I'm going to be outside (laugh, laugh). I'll be out talking on a bench. No more credentials. No more I can't talk to you about that. They used to say you are one of the most effective counselors we have. Absolutely I was. But for me, I was drunk every night. Yes, I was effective until six, seven – because I never went home on time cause the job doesn't let you. But, boy, when I did go home I drank myself to sleep. Not once in awhile. Not on Saturdays. Every night. So this society has created much of what we're facing. But just the recognition that trauma exists, that mental illness is something that people can recover from. Do you know, it was only consumers that made them say that? Why? Because the system is the medical industry. You'll tear the medical industry apart if people really believe in that philosophy.

You'd think they'd know that.

Yes. So, they fight us. They fight us, you know. And that's what the current administration is, is doing. It's saying well, we're not sure – you know, you're not on the right side of this issue. We don't quite like your interpretation. We like the side of it, you know, there's a lot to be said. Don't talk about the medical industry because you'd be in trouble with us.

TAPE 2, SIDE 2

You co-founded the National Consumer Survivor People of Color nationally.

I co-founded the National People of Color Consumer Survivor Network after going to Alternatives and discovering we didn't have a place on the agenda. We were in the room, but year after year after year, the only time you saw people of color – African-Americans and others – was at something they called the caucus. Well, after awhile it became a joke to have this caucus, you know what I mean. We'd have a night – Wednesday night at eight o'clock we'd do the People of Color caucus and then they'd come up with all these plans and all these ideas and then with no money and no way to communicate with each other, it was over.

It was a ghetto.

Absolutely, ghetto, ghetto, ghetto and I said, okay, let's see if we can find another way to become more of a piece of this tapestry rather than a viewer. Let's see if we can get to the front of the room. Those were my words. I want to see African-Americans in front of the room helping set the agenda, helping to talk about what the issues are, blah, blah, blah. So, we got a little bit of money from them so we had an African-American meeting. We

had a people of color meeting. I always wanted to be African-American. That didn't work well with some of the other people. There was a vote, they voted to be people of color. I went with it because I was just one person. We had a meeting of people of color. Twenty-five, twenty-eight people came to the meeting. It was an effective meeting. But the format of the meeting was not what I would have wanted. What the format was, was that people from all government agencies would come and talk about what that agency did and how that agency could help. How? What do you mean how could it help? None of the things they said helped me. None of them and I was fairly sophisticated. I didn't know what to do after they left. I saw them. I smiled at them and they left and I never saw them again because I didn't know how to reach them or how they could actually help me or the group of us as individuals. They didn't talk about that because they help states and they help the universities. But they didn't help little people. So, why did they come there and tell us that? Because they didn't help us to get in. So, I decided, okay, I talked to the group there – my presentation to the group was with all of the other things that people are telling us we can do, I have one simple thing that I would like us to do. There is a big field coming up and private industry is paying and mandated that if they get monies to do certain types of work, they have to do something called "cultural competency." And cultural competency is different from just reading a book on culture. It is an understanding of meeting people how and where they are. Of looking at, for instance, the mental health system through the eyes of a Hispanic consumer. What does that mean to him and his family. Looking at it from the point of view of a woman from Haiti who would both be an immigrant and maybe black but not be black American. How the culture and how she – how does her world as she knows it and experiences it, impact her mental health when she has to go to the hospital. What's different and what would we want to say if we were going to her community to help to build a bridge for her. These are the things. I said since nobody owns this cultural competency thing, this is six years ago – nobody owns it, why don't we take a stab at having us become trained as cultural competency experts. Why don't we get someone in to train us. Help us become cultural competency experts. Help us then to go back to our various places cause we all were two here in this group, two here in that group and in some instances two in a state. Two people of color in a state that were advocates in the mental health movement or the consumer movement and let's go there and let's then add to our groups, individual groups, and then we would not be coming and taking that one chair that they're so scared of the five chairs they've had for the last five years. The white consumers who started the movement who don't want to give up a chair. We could create a new chair. We could also bring to them a new skill and a new understanding and they can then go out and join us as people who know this work and they can write it on their resume that they can understand and they can do

this piece, too. So, we all – it's only a win-win situation. Nobody's going to lose. And so the group thought, well that sounds like something. If you do all the work, you can do it. So, I did. I did the work – I did a lot of the work. I had a couple of colleagues that did some of the work and we got together – we got a little bit of money, and we went – we decided we would do this one day, two day training, I'm sorry – at Alternatives. And everything was very difficult because Alternatives – the people putting it on that year didn't really want us to do it there. They saw it as divisive and they sort of said that and made it come true. So, we wanted to have it two days before the meeting. There wasn't enough money – at least the government said there wasn't enough money – so we would have to have it the same day as the meeting which created – that was the detriment right there. So, while they were trying to have the traditional Alternatives Conference – they had always had people of color interspersed – all of a sudden, there's no people of color there at all the first two days because we're in the room meeting and that created a lot of conflict. Where are the people of color? They have to go to a meeting. Can you go? No, you're not allowed. And it created a – it gave a lot of people who had been waiting to slap down this colored people movement – it gave them an opportunity to slap down. So people were coming out and saying to – say a group of ten white consumers brought one Hispanic consumer with them. Well, all the way home, all these white ten people talked about was how offensive that was that they were off in that room and how that offended them. This person has to live with them for another year. They brought that person and – it created so much pain and so much misery that we just truly failed at what we were trying to do. But even though we failed, I kept on going. I came back to Temple and, and started doing an advance course in cultural competency looking for a way – because the course I'm taking is designed you to effect policy, to change policy with the understanding of cultural. I went there to understand as a black female could inculcate black, being a black female into this movement. What I learned there was totally different. I learned all about other cultures and how I could understand their cultures better and how I could see the similarities and how I could become a better listener and how I could become a student of learning about other people – which was totally different from why I went there. But what a wonderful gift to have a different framework and it's a beautiful, beautiful idea. If I was sort of not been as active as I wanted to be at creating this cultural competency expertise within the people of color, but I think it's still doable. It's just not something that I'm doing right now – going to school at Temple and I'm working very hard on the trauma piece and in addition I'm doing keynote speeches and representing consumers on many other things besides the President's Commission. I went to the White House with Darby Penny which she wrote about in the paper which was really the truth, you know. I always refer to that paper and that instance of being invited and thinking

I'm going to be somebody and they never even looked at us. They didn't even see us. They just – you know, just so many – but I've been able to represent many consumers in many, many places. I've been at the table. I've been a part of lots and lots of forums. I'm really proud of a lot of the work that I've done. I will not be happy or satisfied until African-Americans specifically and people of color generally, have a voice at the table – a permanent seat and that they stop – and when they do give us something, they give it to white people to manage for us and they choose us and then give us. No, that's wrong. Absolutely wrong. And that has to stop. That definitely has to stop. They have to give us – they're obligated and mandated by law to not only give us the money, but to give us the technical, the technical help and support to make it successful. That's a mandate of the government, the law – but they don't follow through. So, I'm hoping that some day we'll come again – some people who are interested in doing the things that I know need to be done, but can't do. Don't have time. Don't have the energy. Don't have the resources. What I do have the resources to do is – at the end of the trauma study which is coming to the end right now – it finishes in September of 2003, it's a five year study – it will be finished. I realize that nothing in that study was bringing to bear on the women about color and culture, especially African-American women. They are thirty percent of that study turned out to be African-American women, but nothing within the study – the way it's programmed, the way the protocol is developed, analysis – addresses that. So what I've done is, with the help of SAMSHA, decided to do a monograph just on the African-American woman who is traumatized and do something about that and because I don't represent – I don't think representing myself because I'm too into the culture as it stands. I don't think I have a true perspective like I did ten years ago of what it's like to be an African-American woman trying to get services out there now, I'm organizing what I'm calling a black woman's round table. A round table is different than an organization because a round table comes together to address an issue, create a product and then it dissolves or disperses. I'm hoping that this one won't cause I'm going to use this round table to educate. I'm going to give them everything I know. I'm going to pull everything I've got to help them to understand trauma as I understand it. To help them interpret what has been written so that on the day when that study publishes its material, we will have material – we have come together at least to agree on what – I don't know the word, but the first piece. We're going to do a major paper, maybe a few brochures, maybe a how-to guide, but our perspective on trauma is going to be different than what the study's is. The study is addressing the public mental health system gearing it mostly towards individuals called therapists clinicians. My work will be the public mental health system as it is viewed from the community basis and it will be directed toward community activists. It will be so that mothers can talk to their daughters. In this house, if you come in here or

we're watching TV and something comes up that has to do with trauma, we stop everything and we go into a discussion. Everybody here is educated. We look – we're educated through the – we have lenses, trauma lenses in our house, on ourselves. You should see how much more sympathetic we are to those of us who can't get out of the hole. Who keep walking and falling into the – such a difference then that mean spirit – we're sick of you. We're tired of you. You're dragging us down. That's not here. We look. Sympathy with empathy and with love and we love you through as best we can. But we also learn to take care of ourselves. My family today, my grandchildren still experiencing many of the issues that their mothers, my children, and their fathers, my children, experienced. The basic difference for me is that I know how to do damage control and take care of myself. I take care of myself no matter what's going on and I can do damage control to whatever is going on with them. I don't see myself as having to save them or save the world, but I do know how to do much, much damage control. I know how to ask for help. And if you want to know what my biggest accomplishment, that's it.

How do you – is there ever a conflict between your desire to help someone else and wanting, needing to help yourself?

Not in here, no. I'll give you an example. When my great grandbaby died, that's Tramale – that's her twin that you saw in her arms. When my great grandbaby died, it was like all the life was tore out of me. So I just came upstairs, got into bed and six people got in there with me (laugh, laugh). It wasn't that I stayed downstairs acting like the brave great grandmother, you see. But they all knew that it was a moment for us just to be with each other. No, there was not a problem between me and them in taking care of myself. It encouraged – cause all I do is encourage them to do what I did. Encourage them to rest. Encourage them to cry. I encouraged them to use the same tools that I use for wellness. So, no, it worked well. Very, very well. And when at the funeral, we didn't do long – I knew not to do a long drawn out funeral thing. You don't do that because that just enhances people's pain. So we did a very short thing. We had – the Muslim imam did a little thing that he has to do that's required, you know, through the religion and then I went to the front of the room and I talked to my family. I talked to them and I made it very clear that unlike the old days where we would have seen this as something we had done wrong and we were paying for it – that's not what was going on. This wonderful little soul that had been leant to us for a few minutes had been looked at with some power higher than us and said, you know, you don't really need to learn all those things other people need to learn, you can just come on back because you're perfect. And for us so we don't have to feel any shame, blame and guilt because those are the dynamics of trauma. We don't need them. Where there's no shame, we can actually

take care of each other. We don't need to blame. None of us did it. We understand clearly what happened. It was SIDS. There was no guilt. We were there every day. We took such good care of her that we could talk about that. Let's celebrate it. Without even knowing that she wouldn't be here, look how we treated her. So it's a loss but it's not a shame. And my daughter, her grandmother said, that was the first time that in all years, and years and years that she felt that I was talking directly to her and telling her don't take this on as a burden. It's not your burden. It's not a burden. It's just a loss. It's not a burden. You don't have to wear this on your shoulders like a mantle. This is just one of the things that happened. My daughter said, "I remember every word you said, mom. I remember how you just talked to us, you called our names, you told us what was going on, it was so good." Damage control.

I just have –

Two more minutes on the tape (laugh, laugh).

I'm sorry. I'm just a little –

A. It's a moment. It's a moment. You can take a moment. See, that's what I'm talking about. You don't have to talk like you have to go back to that piece of paper. You can just sit there and do nothing like I will. It's a moment.

Q. I can use a cigarette.

A. Okay. You can have it. I take a nap every day.

Q. (Unclear) the benefits of that myself.

A. Oh, I don't know.

Q. What's the, what's the toughest challenge do you think that, um, consumers face in the mental health system today?

A. Ahh, I have to answer that in two ways. I think I have to answer it on a personal level and on a professional organization level. On a personal level, I think it's knowing how to do self care – taking care of yourself. Understanding what the limits are to what you can do about any situation whether it's your child, your best friend, your partner. Knowing what the boundaries are. Your limitations and what the boundaries are. Not only what limits you but what should limit you. That's very difficult because once you get to recovery you sort of think of yourself as a person who can then help everybody and that's not possible cause the environment is not

there. The support – there has to be a different environment for that kind of vision to take place. So, that's the biggest challenge – self care. When you're working knowing when it's your chance to have the, ah, support and the time for you and to do what needs to be done. Loving of self is just more than love. It's bringing together to bear the resources that you share with others for yourself. So often that's a missing dynamic. Having that time every day, every single day to just to have a moment of real good wellness. Nobody teaches you that. They teach you there – well, now at least they're accepting that you can go after recovery, but they don't tell you that one of the dynamics of recovery is day by day. You're not recovered for life. And the reason this is so critical is because when you get that job, when you struggle back to health and you get in the movement and you get a position that you like and you're doing work that you want to do and then it doesn't work? You can fall all apart again. Totally apart again because you're not prepared for disappointment, for challenge, for barriers, for that kind of attack on you. You take it personally and then you're gone again. This has happened in the last year to – in the last six months, to major African-American leaders. Both of which had excellent, excellent jobs – one of which is in New York have both been terminated from work that they've done almost as if it was a vision. You know, they brought that kind of fervor and love and interest and personal self to their work and they've been fired. I predict that both of them will need a great deal of support and may find themselves back and very much at the gate of the (knock, knock) some sort of institutional or some sort of support for their mental health issues again. They may fall apart. Actually three – it's not two, three. Two from New York.

Q. I think I know one from New York City.

A. Ah huh. So, that's the biggest challenge. The biggest challenge is not being successful in recovery but staying in recovery when you're not being successful – when you're being attacked or when things don't go well. I don't have a job. I don't have a job. Not because I'm not capable or prepared but because I couldn't bear to be fired. I couldn't even bear – I couldn't bear to be fired. I would be sick. So, I'm not going to take that risk. So that's the personal and the organizational. This thing is very tenuous. There is a recommendation that I have for that and let's have a dialogue about it. Let's talk about what does it take to hire a person like me or like these colleagues of mine who are African-American who over the last year have all lost their standing. What does it take to hire them? What kinds of supports do they need because what is being done is they're being hired but the supports they need are not being given to them. They're very busy developing supports for other people, but nothings being done for their particular need cause they haven't identified it as a need yet. So, that's the biggest challenges as I see it from a

personal point of view of a consumer. Um, from the point of view from an organizational point of view, is to have there be – to get through this possible crisis where the three major entities – the technical assistance centers – might not exist and not to go back to step one because they don't exist but to stay where we are. To hold our ground collectively in some unified way rather than to peter out in a hundred different ways. To hold our ground and make sure that if it is not those entities, it is some entities because we can fight and win that fight. We might not be able to win the fight for the three entities as they are. I don't know. But I know we can win the fight for some entities, whether it's three, five or ten. I know we can. And that to me is the biggest challenge for consumers, you know in their twenties.

- Q. Do you think that there is a strong movement today among – let me rephrase that. Do you think that the current climate of the administration, the way they're kind of supporting that traditional system, um, do you think that's influencing the state of the movement? Do you think – before I got this job – I mean this job is a real education for me. I was working in mental health before, but never really had the access to the information and the people that this job affords me, and I understood about the movement and I've learned about the origins of it and it just appeared to me that as I was going along, there's, as you say, a lot of splintering and dissolving. A lot of people blaming each other. What do you think is the cause of that?
- A. The cause of it? Remember that I told you that even from the very beginning when you have a mental illness, the first things that you remember is being blamed for it. Mental illness is something you get blamed for having, you know what I mean? That's endemic. That's everywhere. That's no different in any family. I don't care how rich your family is, what color it is, you're going to get blamed because you're not getting better. We gave you everything. You're not, you don't be well, you know. That's big. So, blame game - blame, shame and guilt go with mental illness like it's three little sisters – it's three big sisters, you know. And in addition comes the rage you feel at being blamed and guilty and shamed for something you didn't do. You didn't do anything. So that handful of components need to be looked at and need to be – stigma, discrimination, blame, guilt, shame – they need to be openly discussed as what happens to people with mental illnesses so that people with mental illness can feel free to move on to the next step. Cause all you have to do is slap a handful of that up against somebody face and it stops them dead cold. It's like a lightning bolt. You just push it in their face whatever time they are most vulnerable. And remember, people generally with mental health issues have multiple vulnerabilities. They're not just vulnerable because they have mental illness. They're vulnerable because they're

easy to shame – you know what I mean? They're set up. They're set up people and, ah, that's important to know. We need to do TV ads on it. We need to say if a fire breaks out in your neighborhood, don't immediately go look at the people who have mental illness to see if they started it, you know what I mean. We need to kind of look at that. If the neighborhood changes, it's not since we put the, the halfway house there, you know what I mean? It's that whole thing. Our society like that, though. Our society always looks for scapegoats. It's a scapegoating society and we fall right into it as a people.

- Q. I would imagine given that Kendra's Law – or involuntary outpatient commitment is a perfect example of the blame game. What is it? I think I know the answer, but what is your feeling about involuntary outpatient commitment?
- A. My feeling about involuntary outpatient commitment is that it is a lie. It is lie when we tell people this is not against your rights. This is not prison or imprisonment. This is not coercion. This is good for you. It is a lie. Anything that you do for me that I don't have a choice about, is not good for me. If we can't come up with a way to have people want to be well, how can we force them to be well? If people have conditions that don't allow them to live in the same way and follow the same – and hear the same music and dance to the same dance – how can we force them to dance it? I think the lie is that we try to make the general public believe this is for their own good. It is not for their own good. It will come back to haunt them. If you force people to do things that's against their will, at some point they'll rebel. And yes, there is that thin line between my rights and yours, but they should be compromised. They should be established in a way of compromise. It should be individualized. It should be individualized and each person should be asked to help to work out their wellness plan. And it should be done at their prime health moment, but when they're sick and in trouble. There is a way out of the involuntary treatment and that is every single person should be asked what would you do – what do you want done when you're ill? How do you want to be treated? What helps you? What helped you before? What have you heard from another consumer that helped them? What would you like to try? And do that for their whole life time and they should carry it with them. I carry mine. You don't need involuntary treatment if you get me at my best and we be getting to work and I believe you're working on my behalf, we'll get there. But to mandate for me to take a medication that you wouldn't give to your child or your mother, what am I? Ask me what helps. Spend the time to educate me. Give me the choice of medication. So, you believe I shouldn't take this one because you don't think it's good. But if I think it's good, let me take it and if I take it then what else can I do? You don't want me going into a training program because you don't think

work is good for me? Or you think I should be sewing buttons on something? Well, let me try. Let's say I'll try for two months. If it had been me and they had – and the doctor had not found that woman to go with me to the meeting, look at what would not have happened. But a traditional medical doctor would never have allowed me to pursue that opportunity. It's ridiculous. A woman who can't leave the house can go to a meeting. Well, it was about what was wrong with me, so it made sense to me but I couldn't get there on my own. But they would have mandated that I have a certain medication to go and then I wouldn't have been able to think about what I needed to think about. Who's in control? Are we in control together or is it just your call?

Q. Since this is being recorded for the State archives and it's going to be here as long as our education building stands, is there anything else that you would like to add that we didn't cover in the interview?

A. I'd like to add to all the children, adult children, of parents who have mental illness, I think every single one of you should remember that there's a great deal of pain in your life no matter where you are and what you're doing that makes you vulnerable and that you should do whatever you can to find out all about this mental illness issue – to look into your own past and resolve some of those pains because one day out of the blue that may come back to haunt you – the fact that you've been asked to close the door and not deal with it. You are vulnerable and you need to know it and you need to go explore a wellness plan for yourself. You need to stop hiding behind the bushes and stop saying its what your mom did or what your dad did or what your grandparents did and you need to look at what the effect is on you. It's a personal thing. I'm not asking you to help them. I'm asking you to help you because you don't and it hits you, you got all that blame that you've been blaming on someone else and now you see that you didn't take care of yourself and it can really be devastating. And you can end up sicker than any of us. Such a painful piece of knowledge. But now while you have the time, now while you're reading this archive and it points to you, go do some reading, do some looking. Go find a way to be well yourself. Go look. That's it.

Q. Thank you, Jacki.

A. Thank you.

END OF INTERVIEW