Keris Myrick talks about consumers’ defining their own recovery…

…ask ten different people and you'll get maybe fifteen different answers. That's recovery. There is no – for me – one definitive answer because it's so individualized that it is the individual's response to the question that defines recovery. That sounds a bit elusive, but I really do think it is – recovery is dependent upon an individual and how they define it.

So how do I define it? It's being able to achieve my goals and dreams in life, having the supports necessary to do that, having lots and lots of information to make informed decisions about my treatment (she chuckles) that also has a place in recovery, if you will. Having access to anything that I decide is treatment, or call treatment – having access to that – and being respected and honored and seen kind of as a whole person. That's *my* definition. Somebody [else] may define it differently.

And also, when I make a choice about something, to have that choice honored. If I make a choice about not taking medication, in the mental health movement, that's pooh-poohed. When my aunt, who was diagnosed with Stage 2 cancer and went through chemo, and it was really hard on her—she's not really my aunt, but she's my cousin, cousin, cousin, cousin kind of thing. But my understanding was it was very hard on her and she made a decision that she did not want to continue with chemotherapy, and that she just wanted to find a natural way that's even better – that kind of stuff – to take care of herself. The doctor said, "You sure you want to do that? I might not advise it. Is that what you want to do?" She said, "Yes, that's what I want to do." Everybody supported her. I say I don't want to take medication and people force me.

So I think being allowed to and honoring a person's choice in what they want in their treatment toolbox and what they don't want in their treatment toolbox – being fully supportive of that.

READ THE FULL TRANSCRIPT BELOW.

INTERVIEWEE: **KERIS MYRICK**

INTERVIEWER: **Troy Gabrielson**

DATE: **February 3, 2010**

I. Childhood and Education

TG: Today is February 3, 2010, and I am here with Keris Myrick to do her interview for the DMH archive. To start, I'd like you to just tell me a little bit about your background – where you grew up, where you went to school. That kind of thing.

KM: Okay. I'm known by other people as an army brat, (chuckles) but I like to call it a global nomad because I don't think being an army brat was so bratty. So I was born in Bremerhaven, Germany, and lived there until I was six, and then we moved to the United States and we lived in Southern California while my father was completing his doctorate at USC Film School. And then from there, moved around the world and parts of the U.S. for most of my life.

So going to school – I wouldn't remember the names of all the schools – basically high school in northern Virginia, Langley High School. Then from there I attended Wellesley for one disastrous year, which is in Wellesley, Massachusetts – all women's college. And dropped out of school at that time for ten years, I think it was, and returned to school ten years later at Temple University, and graduated from Temple with a Bachelor's in Business Administration. Then went on to Case Western Reserve University for business school, where I got an MBA, with a focus on marketing and research.

And then moved out here to go to Fuller Seminary. Long story about that. So I went to Fuller Seminary and have a degree – Masters in Divinity – that I don't use. It's just there. Now I have a Master's of Science and Organizational Psychology, and I'm completing my Ph.D. in Industrial-Organizational Psychology at what used to be called California School of Professional Psychology and now is called Alliant International University. That's it. That's the whole school thing. (laughs)

TG: Yeah. So it sounds like with your B.A. and then the M.B.A., and now even with the Industrial Psych, it's like you have a particular interest in kind of the business side, the organizational side.

KM: Kind of, sort of. I mean, the Bachelors in Business Administration was not—it was more around—I had an interest in marketing and how people make decisions around either purchasing things or loyalty to things. And then the statistics part was—I had a double in Statistics to do the research part. So I kind of had an interest in research, research and people. And when I was working, I became interested in how do people work in organizations, how do they function together, especially as a person of color, when you bring people together from different backgrounds, traveling internationally, people from different backgrounds, and how do you come together and work well together? So that's what led me into sort of the organizational psychology sort of thing. So, yeah, I guess it's the business end, but it's the people in the business. How does all of that work?

TG: How do all these different kinds of people come together?

KM: Yeah, yeah.

TG: What does that look like?

KM: Yeah, what does that look like? God forbid you spend your life working and hating your job, so how can you make work more enjoyable? How can you help people make wise decisions about where they're choosing to work? So if it's not a good fit, that's okay, but how, then, do they think about what type of work they might like to do and where things might be better for them? That kind of thing.

TG: Yeah. So as you were completing these degrees, did you have a particular field that you thought you were going to want to go into?

KM: No. When I went back to school to get the marketing degree – I remember distinctly, my mom and I were in the parking lot arguing because I was interested in human resources. Obviously, humans are resources in a business. So I was interested in human resources, and she was like, "Oh, you don't want to do that." We were just having this intense argument, and I thought, ugh, you know, just to shut her up – I hate to say it – I just opened the catalog at Temple University and put my finger on it and said wherever it lands, that's what I'm going to study, and it fell on marketing. So there was no rhyme or reason to it initially. It made sense in the end.

And then when I did go back to school for the Ph.D., I really was interested in, specifically, selection theory [the study, from a more objective standpoint, of how people are selected for jobs, college, etc.] because I was working in college admissions and working with all sorts of people – young folks all the way up to returning students – on how do you select colleges? And then, on the other end, how do colleges make decisions that make sense in selecting students that aren't 100 percent bound by SAT scores and things like that? How do you take into account all the other factors in order to make decisions in student selection?

That's really where my mind was for a very long time, and then I guess I had my epiphany moment where I was like, "What? No, that's not fitting." College admissions thing – I really love it, and I still kind of do it as a side thing, but I really enjoy helping people grow among their work, so I switched a little bit.

II. NAMI Involvement; Early Work in Mental Health; Project Return

TG: So what were the circumstances and thoughts that led you to end up working in mental health?

KM: Well, I've been encouraged to do it for quite some time from both my (chuckling) therapist and my psychiatrist. I think they were thinking more like clinical works. I was working well at the time with kids, especially kids who have autism or Asperger's [a psychiatric disorder whose symptoms include social and communication abnormalities], for some reason. We all got along and it was enjoyable work, and I like working with the kids and families, and they like me. But I thought that would be too hard for me because I'm a pretty sensitive person, and I would worry about what things they would tell me in a session and me wanting to hug them and make it all better. (chuckling) That's not really the role of a therapist, so – no, I get it, but I don't think I have that kind of ability. I had heard about how this peer work, this certified peer work, and how a person with a mental illness can use their lived experience to kind of inform their work and be a peer to another person who has a mental illness, which really makes, intuitively, a lot of sense. So I got more involved in learning about that and sort of different organizations, NAMI [National Alliance on Mental Illness, a prominent family advocacy organization] being one, and that sort of thing. That's how I got into it. And it's a much better fit. I mean, it's much better.

TG: Yeah. Fits better with that really sensitive side?

KM: Well, yeah, even though a lot of people don't see the sensitive side. I kind of hide it a little bit. But I think it fits better with allowing for creativity. I suppose something in mental health allows people to be more creative, whether you're a practitioner, a peer, a supervisor running an organization. There's a level of creativity – of course, you're bound by all of the lovely rules that we have to follow, but within that I feel like I'm allowed to be way more creative, where in admissions work, which is interesting, you weren't really allowed to be creative. You kind of had to do it the way it was always done, or follow certain rules. Thinking outside of the box was not really appreciated. So it was that that I struggled with and didn't realize it. Where here, the encouragement is, "No, [do] think outside of the box. Not outside of the rectangle, come back in." (laughing) But thinking outside of the box, within the rectangle, is a good thing. So I think that's where the fit is better.

And I guess having to think about – I don't think much about my illness or how it impacts my work, but I can use sort of my lived experience to talk with other people about what they're going through. Sometimes it informs my work or my work schedule, or it informs how I think about our job descriptions here and do they make sense, and all sorts of things. It's really interesting how I can use that in a positive way, where I think it isn't a detriment. I don't have to run around with my label on my forehead or say I have a diagnosis or any of that. But being able to speak freely about it, where sort of in the admissions world and the other worlds I've been in, it's something nobody knows about. Like you don't talk about it, you don't share it. If you are having a hard time, if you're hospitalized, you say you're out sick, or you're going on a vacation, or, you know, you have all these euphemisms. But here, you don't have to do that. It's pretty empowering.

TG: Yeah, absolutely.

KM: And a lot less often I have to say I'm out sick or on a vacation, where before, I think you say it more because it's happening more, because you can't really be your authentic self. There's a pressure in that.

TG: Yeah. You mentioned your lived experience and I know you've been involved with NAMI. Can you talk about how you first got involved with NAMI and what that was like and what was going on there?

KM: I had my first hospitalization out here in California. I've been living here now I think thirteen years. I was diagnosed when I was – well, many times, but I guess the one that kind of – was the one where they medicated me and all of that was in Cleveland. But then when I got out here, I got sick and was hospitalized. When you're discharged, you get discharge paperwork from the hospital that says, like, when's your next appointment with your therapist, what medications are you taking, are you clear about the medications and the dosages and when you take them.

And then on the back side of the sheet, it lists a whole bunch of organizations, and they check off different ones that you might want to try. It's sort of support and education kind of organizations. They had about three of those checked off. I called one but couldn't get an answer, so I kind of gave up. I mean, you're right out of the hospital. It was like, okay, I probably called twice and gave up (she chuckles). You know, you're still kind of getting—they leave you now in the hospital three days, and after that they kind of let you go as if you're 100 percent functional, which you're probably not.

But anyhow, I kind of gave up on that one. I was able to find the second one and went to it and just felt really uncomfortable. I don't know. And I took this approach of "not for me. If it works for other people, great," but something about it really didn't fit for me.

And then NAMI was the third one, and I called the 1-800 number and they gave me the information about the closest affiliate to me and when they were having their next, what they call, Care and Share meetings, which are these support group meetings. And I've written about this and had this published a couple different places, but it's so hilarious. I walk into the meeting and it's—they've seen it, so I can say it, but it's NAMI San Gabriel Valley, which was the Pasadena, basically, affiliate – Pasadena, Altadena, kind of San Gabriel area, La Cañada kind of thing. And I walk in, and at first I'm thinking, "Okay, I've got to be in the wrong meeting," or "Wow, is this the right place?" I mean, it's three old white ladies (they laugh) sitting at a table, and I'm like the young black chick walking in and kind of going, "Wow." And I said, "Is this NAMI?" And they're like, "Oh, yes, dear. Come in." And I'm like, "Wow. Okay." So I'm thinking, "Okay, scratch off number three. I'm not having any luck with this."

And so, of course, I'm the new face in the room, obviously. So they kept asking me – they were talking mainly about their adult children, and I'm just sitting and listening 'cause this is all new to me. So then they're asking me about, you know, "Who's the ill loved one in your family?" And I'm like, "What?" And they said, "Are you a family member?" And I'm thinking, "Sure, I'm a family member. Isn't everybody a member of their family?" I mean, the whole thing is, like, this foreign language. I don't know what they're talking about.

And they said, "Who's the person who has the illness in your family?" And I'm like, "Well, me." And then they're like, "Well, then you're not a family member." And I'm like, "What?" And they said, "Well, you're a consumer." I'm like, "What?" I mean, all of this is like—like really, I've stepped into another world. And I said, "Okay." And they said, "Well, really, these meetings are for family members, and we don't really have meetings for consumers." And I'm just kind of like, "Oh, okay."

So I told them how I had heard about the meeting, and I said, "Well, I just got released from a hospital – " and I told them which hospital – "a couple of days ago, or a week ago, whatever it was. These were the numbers that were given to me, and that's how I ended up coming tonight. And I'm sorry, I didn't know that—" so now I call her my NAMI Mommy, the woman who did this – she was like, [with a concerned tone] "Oh my, dear, oh my. Did that really—why were you in the hospital, and what happened, and what were you doing before, and what are you doing now?" And, "Oh no, you're going to stay. You just stay here. Here, have some water." And they just started doing this caretaking thing, and they just kind of welcomed me in that way. (laughing) It was a little weird, but—so now I have these three white NAMI Mommies. What can I say? (TG chuckles)

So that's kind of how I got involved. And NAMI San Gabriel Valley is what I would call an older affiliate. It's older in tenure and the new members tend to be moms and dads of adult children [with a mental illness] – around my age or older, actually. When I started going to some of the other meetings – their general meetings and their educational meetings – I was sort of seeing a lot of people who didn't look like me, but again, I have no connections here, I have no family. I have no connections here. So it was a bit of a connection, and I was learning some things. And to them, I was, like, a warm body, so the next thing I knew I was on the board – [enthusiastically] "Oh, a warm body! Put her on the board!" (chuckling) So probably within six months I was on their board, and that's how I started to learn more about this thing called "consumers" and "families" and the dynamics that happen there, and sort of some of the things that NAMI was about and involved in. And just became more and more interested and felt like it was a safe place to be, of sorts. And sometimes not so safe, to be honest.

So that's how I got involved. It didn't take long before—I think within my first year, I had gone to a state conference, because it was in the southern region, and went to a consumer council meeting at the state conference, where there were probably about fifty consumers from around the state, and they were trying to organize and have a consumer council and a committee. And they asked if people were interested to sign up, and you just fill out this application kind of thing. I filled it out, and they continued to call and ask if I wanted to be more involved in sort of setting up the committee.

So I was with a group of, oh, maybe ten of us initially, that were flown to Sacramento for sort of a strategy and planning meeting with the executive director at that time, to sort of set up the consumer council committee.

And from there I was nabbed for everything in life. It was like, "Oh, well can you come and do this, and can you come and do that, and will you come and do this?" And I was like, "Okay, okay, okay." And just got more involved with NAMI California. Usually, there are things you do in the State that are related to [NAMI] National, so the next thing you knew I was involved with NAMI National. "Oh, can you send Keris to do this?" and it was like "Okay," kind of thing. That's kind of how it went.

TG: And when was that that you first went to NAMI, that you went to the Share and Care meeting?

KM: Oh, Jiminies, I'd have to look at one of my articles. I really don't remember. It seems like three years ago, I was saying it was eight years ago. So ten years ago? Maybe I'd been here three years before I was hospitalized, I guess. Yeah.

TG: Okay. So you're here [in Los Angeles]. And how did you become involved with MHA [Mental Health America] and Project Return? [Mental Health America is a mental health advocacy organization and the parent of Project Return, a consumer-run mental health support network.]

KM: Let's see. I was still, at one point, I think, doing admissions work while I was kind of off doing this NAMI thing and learning about NAMI, probably more at the local level at the time. Yeah, because I remember where I was working, they gave to the NAMI Walk [a fundraiser for NAMI]. A number of folks in my office gave to the NAMI Walk.
I had been fired from my job and kind of went into a tailspin over that. The day that I had been fired, my affiliate said, "Oh, we're sending you to somewhere in L.A. to become a peer-to-peer mentor." Peer-to-peer is their nine-week – I think it's nine weeks. It's either nine weeks or ten weeks. Nine-week educational course, taught by people with a mental health issue, to people with a mental health issue. And you need to go to a training to be the facilitator for that. It's called a Peer Mentor.

I'd just been fired and I was like, "I don't want to go to this," but I felt like I had told them I would, and I felt obligated to go. I'm one of these people if I say I'm going to do something, no matter what, no matter how sick I am, I try to live up to my obligation. So rather than not go – because I knew there was an expense involved as well, but the affiliate had paid for us to go – I went. Put my dog in the car. My dog slept in the car for the two nights. And I kept trying to leave. And I went to this training and kept trying to leave and go home and say that I wasn't coming back, that I couldn't deal. I was crying the whole time. I was a mess. I was like, what the heck did they give me a certificate for completing that thing, I don't know.

I got very connected to the facilitators, who were Jim and Kathryn McNulty. Jim, at one point, was on the board of NAMI National and was the president of NAMI National. And Kathryn was working for NAMI National as the author of Peer-to-Peer and other peer programs. So we became very close and kept connected. Jim would get me involved in a lot of different things nationally to learn more about this peer support stuff.
And then another friend of mine, Paul Cumming, who's a trainer for Network of Care [a company that offers information on mental health support and advocacy, as well as clinical material] was also kind of like a— I think the term is maven, but he's a guy (chuckling). He knows all of these people and he knows how to put people in touch with people. That's what he was doing, and he was putting me in touch with all of these people. And one of the people that he was really – because I wasn't working, either – really interested was Lori Ashcraft [Dr. Lori Ashcraft, a Director at Recovery Innovations] from Recovery Innovations of Arizona [the Arizona chapter of an organization that provides mental health support services], which used to be called META Services.

I got the opportunity to go out there and visit what they do in Arizona, which was sort of life-altering, about kind of understanding what the whole mental health system is about, what care is about, what *real* care is about versus what kind of not-so-real care is about. I said, "Okay. I want to work for you guys." At the end of the thing, they said, "Okay. Who wants to come to Arizona and work?" And I'm like, I don't have a job, "I'll go, I'll go."

But they did have Recovery Innovations in California, and I started working with them, helping them to set up what they were doing in Ventura County. So I was traveling between Pasadena and Oxnard. And that's how I really got involved in sort of running an organization that certifies peer specialists and supervises and all that kind of stuff. And did some presentations with Lori.

At the same time, I was working as a consultant for the California Institute of Mental Health, doing a recovery-oriented outcome measurement tool called the Clinically

Informed Outcome Management Tool [CIOM, a recovery-oriented self-report survey]. I was piloting it here in L.A., helping with the pilot here in L.A., and had gone up to a meeting and met Dave Pilon, [Dr. Dave Pilon, former Director of Research at MHA] who is now our CEO of Mental Health America Los Angeles [the Los Angeles chapter of Mental Health America]. Met him for the first time, and had been on these conference calls with him, and probably within a couple of weeks he was calling me, "Oh, you know, are you interested in—What are you doing right now?" And, "Give me a call. Call me on my cell phone." I'm thinking, what is he calling me about?

I'd just started working in Ventura, and he said, "What are you doing right now? Are you working? I know you're doing the consultant thing." I said, "Yeah, I'm working at Recovery Innovations." He goes, [emphatically] "What! They got you?" And I'm like, "What are you talking about?" So, basically, he was trying to recruit me to work here [at Project Return]. But I didn't know that, and I said, "No, no. I'm here and I just got here, and I'm certainly not going to be here five seconds and then leave. That wouldn't be the right thing to do."

He was pretty persistent, and he kind of kept calling me and checking in to see, "Well, how are things going? You still liking it?" I'm like, "Yeah. Quit calling me." I said, "Dave, if I quit here and went to work for you after three months here, how would you trust me if I worked at Project Return, that I wouldn't leave after three months?" I said, "So kind of look at it that way, that this is a sign that I'm a dedicated person to what I'm doing, and if things don't work out then it's just because they didn't work out, but I'm certainly not going to jump from one organization to another. In my mind, it just doesn't—I don't like that."

And it kind of did turn out that the commute to Ventura—I was planning to move there, but just never really felt comfortable there – that I decided after six months, when things got really kind of settled in and there was an ability to replace me with someone else.

Then I called Dave back and I said, "Okay. Now I can talk to you." And we set up some time to meet, and it just seemed like a really, really exciting opportunity. Some folks had laid some really, really good groundwork here – Bill Compton and Catherine Bond [former directors of Project Return] and Eduardo Vega [former Associate Director of Project Return], Bill Slocum – many people have just really set this organization on its trajectory, and now it's kind of going forward more and more, and it just felt like a great opportunity and challenge to come here to Project Return.

So that's how I ended up here. No intention. Wasn't even interested. But it was great. I'm glad Dave was so persistent.

TG: And what year was it that you first came?

KM: I will be here a year in five or six days, so February, I believe, sixteenth, eighteenth, something, was my first day here, of last year [2009].

TG: So when you first came it was as Director, is that right?

KM: Yes. I came in as Executive Director. Big shoes to fill here.

III. Consumers and NAMI; Stigma; Clients' Rights and Involuntary Treatment; Hospitalization

TG: So, to go back a little bit, when you started getting more involved with NAMI, and you were on their board and you started learning more about what this was about and the language and all of that, what would you say was a major problem or the major problem that you saw with people facing mental illness at the time? And to go off of that, how have you seen that change, and how have you worked to change that in your work over the years?

KM: I guess—wow, that's really hard, because when I was on the local [NAMI] board and in my local [NAMI] affiliate, I was the only consumer. There weren't even consumers coming to the meetings. I was really the only one. So the problem as I saw it would be very local, which I guess now I can understand is global, but at the time I just saw it as, well, this is my affiliate, because I didn't know about all the other affiliates and what they were doing. But I think there *is* the problem – was that I was the only one. I mean, how ridiculous is that? (chuckling)

But this is what I will say about NAMI – it initially started as a family organization. And as people were becoming more well and had the ability to be involved, nobody thought about consumer involvement in NAMI. It was [seen as] sort of this thing for the parents [of people with mental illness] and children, and now we're talking adult children. We're in situations where they [consumers] couldn't be involved, either in IMDs [Institutions of Mental Disease], or some incarcerated, or some living in board and cares, and so forth. So the idea of having full involvement in a meaningful way really was foreign. But it became their world view that [speaking from the perspective of parents involved in NAMI], "All consumers are like that, all consumers are like my son, all consumers are like my daughter," which is not saying anything negative; it's a natural experience of humans to take their situation and globalize it.

I realize that this has sort of been an issue in mental health for consumers' peers in general, is how do you help people realize that there is a broad range of consumerdom (they laugh) consumerhood? What is the word? There's this really broad range. So, yes, there are people who are in IMDs and who are in locked facilities and who are in jails, which is where mental health folks don't belong to begin with anyway. That's not where you go get treatment. And there are people who are living in board and cares, and there are people who go back to school, and there are people who are working. I mean, there's a whole range of folks, and there isn't any quote/unquote "one consumer" kind of thing.

I think that's the biggest struggle, I think, is maybe that stigma. Maybe that is stigma, or stereotyping, or what have you. When people see someone like me, or someone else who doesn't look like their loved one, not to think that *that* person now is odd. So now I'm odd. So now I'm a consumer, and on top of that I'm odd. It's like, oh, great, thanks. (they chuckle) Because I don't fit into quote/unquote their definition of a "consumer," or what they think a consumer should look like, act like, be like, kind of thing. Whereas, no, [in reality,] I'm just like everyone else, kind of thing. So I think that's one of the things.

The other thing is – I'm not a big, old fan of forced treatment. I'm just not. I don't get it. And I think when I went to Recovery Innovations, the term they used was "trauma." I

would have never thought you could put “trauma” and “care” (she laughs) into the same sentence. They seem oxymoronic to me. But indeed, some of the care that I received was very violent and traumatizing. I think police coming to your door when you're not feeling well and putting handcuffs on you and embarrassing you and taking you out, putting you in a cop car, taking you to the police station before they take you to the hospital, then taking you to the hospital, where you're still in handcuffs, is not the way you treat somebody who has a broken leg. It's not the way you treat somebody who is experiencing back pain. I don't know any other disease in which people are treated in that way, and that's *not* treatment. That's, to me, a little abusive. I mean, it feels harsh for me to say that, but that's what it feels like. It feels like I'm being abused.
So I'm not a fan of forced treatment or restraining people. You know, we have a—I'm part Native American on my mom's side. My mom is Native American. And we have a saying that resistance, no matter how well hidden, is going to result in more resistance. So if you try to—I mean restraint is going to result in more resistance. So when you try to restrain somebody, the natural response is for them to fight back. And the more you try to restrain them, the more they're going to fight back. So in my world view, restraint is only going to exacerbate resistance. So how can we find better ways to work with people when they are in states where they may need assistance but are not able to either comprehend that assistance is being offered and/or recognize that it's okay if they don't want assistance if, indeed, they're not going to hurt themselves or someone else.

Like, how do you talk to someone and kind of get down to—this is what I love about this idea of—you know, I've been there. If somebody had just said to me, “What is it that you want to accomplish right now? What?” And it's happened, where I just snap to and go, “What? You were just trying, a second ago, to put me in handcuffs, and now you're asking me what?” One of the times I went to the hospital and was really not a happy camper, didn't want to be there, and kind of was fighting the whole way, but not against anything ‘cause at that time I wasn't in handcuffs or anything. The only thing I wanted was a drink of water, quite frankly. That's all I really wanted at the time. I could have attended to anything they wanted if they'd just given me a frickin' drink of water and maybe a sandwich. But because I kept asking for it, to them, that was symptomatic of me not being attentive and not being able to focus, and it was [actually] like, "No, it's me being thirsty and hungry." You know, a cigar is sometimes is just a cigar. I think that is sometimes where I think, even the profession, even we as peers can do it – we see each other through our symptoms, and not down to the basic level of what is a basic human need? Food, water, shelter. Those are the three top [needs]—[and a] job [and] security. If we forget about that, then I think things do get kind of ugly.

So I think the system still needs some work in those areas, around how do we meet people where they are, what really is a danger, what isn't a danger, how can we attend to people without forcing them to do things? Great, you can put me in a 5150 in a hospital [a reference to Section 5150 of the California Welfare and Institutions code, which allows for a person to be placed on an involuntary 72-hour psychiatric hold if considered dangerous to him/herself or to others, or gravely disabled by virtue of a mental illness]. When I leave, I'm not any more apt to follow what you told me. And/or sometimes in hospital I don't gain any skills at all. I mean, the goal is to get me on medication, not to help me have skills with how to reach my goals and dreams when I leave the hospital. It doesn't make for a place I want to go back to, so it's always been, for me—I think I've been in the hospital voluntarily maybe three times.

TG: Voluntarily.

KM: Voluntarily. Because every time it's been suggested I go, because it scared me and the treatment was scary to me, I refused to go and I had to be taken. But it was out of more a fear of the hospital and the treatment, and again, people will say, “Well, she didn't want to go because it was her symptoms.” No. The care was crappy. Why would I want to go somewhere where the care is crappy? I'm going to fight you about that. So to take me there involuntarily isn't really—again, we’re ending up in this cycle.

When I was able to express that to my doctor finally, I said, "Look. This is the reason why I don't go. I don't find it helpful. I find the people rude and not really caring. They have a job to come around and do checks. They might as well be checking to see if a pig is in the room. I mean, it doesn't matter if a person is in the room. I just don't find it a helpful place. So I'm reluctant to go voluntarily. I don't like people looking through my things. I don't like using a bathroom somebody else is using. I mean, there's all sorts of things that make it an incredibly uncomfortable place to be that in some instances, don't have to be there, so I don't feel comfortable going. So, unfortunately, you have to force me to go." He said, "Okay. Let's change that."

Unfortunately, (laughing) the next time I had to go he said, "Okay. We're changing it up. This person's going to meet you there." Like he told me who were the nurses on the floor that night. There's this whole education piece that happened before I went. They all had known that I was coming, and they had to kind of use my name and do things to make me feel like I was a person. But unfortunately, when I got there, they gave my bed away, so they put me in a locked unit and didn't tell me that's what they were doing because there were no beds. When they told me they were putting me in a locked unit I said, "But I'm not suicidal. I don't need to be in a locked unit." "Oh, but it seemed as if you said something about being suicidal, so we think we want to watch you." And I said, "No, no. No, my doctor said that this was what was going to happen, and now you're switching it up on me, so I'm not groovin' to this and I'm not going to stay." "Oh, now, you have to stay. We've called your insurance company." And I felt trapped.

When we got to the floor I asked to speak to the head nurse, or whoever the head person was, and I told them, you know, “This is not going to work, and why did this happen, and this was what I was told and why am I now being told something different, and this is why I don't trust the system. It's why I don't trust the system, and if the goal really is to help me, then you need to help me understand why I'm sitting in a locked unit right now.” And she blatantly told me, she said, "This is what happened. There were no beds. We got the clearance from the insurance company to take you in, and there were no beds to put you [in], so we just thought we would put you here just for the night and you'll be out tomorrow." I said, "But why couldn't you just tell me that? Why did you have to lie to me and then make it seem like it was me who was suicidal? Why didn't you just tell me the insurance company has entered into the scene, and this is what happened?" I said, "Because I came here voluntarily. And I’m talking with you. I could have clearly understood that, and then maybe we could have strategized or I could have agreed to come into this unit knowing that I would be out in the morning, rather than now coming here and being, like, furious, mad, and not trusting anybody. Why did we have to go through that exercise? I don't get it."

So by the next morning, my doctor was there at, like, seven in the morning and I was out the next morning. But why did that have to happen? And I know it doesn't just happen to me. So if it happens to me, in my mind, let's globalize it then. (jokingly) I get to globalize [about] what's happening to everybody. (laughs) But you know what I mean.

So I think there could be a lot more work done around honoring the person, respecting the person, and minimizing, or not doing it at all, seeing the person as their symptoms. That was a long answer. Sorry.

IV. Stigma; Civil Rights Movement; Judi Chamberlin and the Recovery Movement

TG: No, no, no. It was great. And we'll come back to that in a little bit when we talk about MHSA, the idea of the whole person. Right now, I want to ask – big question – why you think stigma persists.

KM: So you're asking a person of color – obviously, if you look at me – why stigma exists. I've lived with it all my life. This is such not a shock to me. Again, I think this is where the consumer movement talks a lot about the Civil Rights Movement, and looking at the black movement, and how this is just like the black movement. You don't come out of the womb with a mental illness, but you do come out of the womb as a person of color, and the society treats you in a different way when they see you. Now, imagine doing that in countries where there are no people who look like me (she chuckles). Like Bremerhaven, Germany – that's where I was born. Sure, they see Army people. But even when I came out of the womb, the hospital nurses were like they had never seen a baby with long hair because they don't have many Native Americans. They hadn't seen—to them, it was a black baby with really long hair. It was just, like, this weird thing to them.

So I think stigma is, again, sort of inherent in our society around generalizing – usually taking in negative stuff – and generalizing and magnifying the negative thing and applying it to a whole group of people that you don't know. You don't have any information about that group of people, for the most part, so you take your information from cues elsewhere – media, movies, newspapers, one person, maybe, that you met, one person maybe that said something to you, bumped into you, whatever, and suddenly that is the whole group.

To me, this whole stigma thing is just, like, yeah, and [your point is]? But I think for people with mental health issues, you don't get diagnosed maybe until you're 16, 17, 18, and so you don't start to understand these things or recognize these things until that point. Where, for a person of color, you recognize it practically as soon as you're born and have cognition and have to interact with people.

So I think it's about the Other, and just ignorance – "ignorance" meaning not knowledge, not having accurate knowledge about something that is unknown. So you fill in the blanks with what you know, even though what you know can be inaccurate, and it suddenly becomes the norm for that group [in your mind], even though [in reality,] it's not [the norm]. I think the media doesn't help. It's not exciting to people to hear good stories about people with mental health issues doing good stuff, but "Ooh, yay, let's watch the story about them doing bad stuff." And the same type of stories – killing someone, hurting someone, that kind of stuff. It gets magnified and there's not a balance of reporting.

I think even if we look at media in the last couple of years, we've seen very positive images of people with mental health issues in mainstream media – on television, as well as in movies. But I think we're starting to swing the pendulum, now, the other way. I went to the movies for the first time in about two years, I guess, a movie theater, and saw trailer after trailer – I mean, there's a movie called *Crazies* [released in 2010] and it is just, could it be any more stereotypical? There you go. The next movie is about some kind of haunted movie that is at an institute for the mentally insane [*Shutter Island*, 2010]. And again, images that—(rhetorically) have we seen these before? It was literally movie after movie. Now we're back to the negative images. We've just swung totally the other direction.

So I think the best way to combat stigma is—I mean, obviously, it didn't work in the media. [*A*] *Beautiful Mind* – it didn't work, in my book. [*A Beautiful Mind* is a 2001 film that is based on the life of Nobel-prize winning economist and mathematician Dr. John Forbes Nash, Jr., who had schizophrenia.] I think, again, it's sort of – what do they call it? – social group theory, where if someone is different than what your picture is of the group, then that person is [considered] an anomaly, versus everybody else could be like that person. So, even growing up, people would say, "But you're not like those other black people." What the hell does that mean? You know, "You're not really black, you're not like those other black people. You don't talk like them, and you have an education," blah, blah, blah. Which is based on a stereotype, and rather than saying, oh, I'm the stereotype and really everybody's like me, it's easier to say, "No, that's the norm – that stereotype is the norm – and you're different than the norm."

I think we're just experiencing what happens with otherness. And I'm not trying to say, oh well, so let's go on with life, but I think places like Project Return and things that the consumers are doing in NAMI, and so forth, is sort of meeting stigma straight on in a one-on-one way. I think the best way to reduce stigma is for people to meet more people who are [seen as] the Other but actually don't fit in what is in their minds about what that is.

We do a lot of panels here. We send a lot of our members and staff out to do panels at schools, to do talks with the Sheriff's office, to do, you know, lots and lots of different places, churches, things like that, because that's a good way to do it too. Did that answer the question?

TG: Yeah, absolutely. And it was very interesting, too, because I have heard the Civil Rights comparison, and so it's very interesting to get another perspective on it.

KM: Yeah. You know, (jokingly) yay, they've borrowed from the Civil Rights Movement again. I don't want to belittle the fact that they look to the Civil Rights Movement as a powerful movement that enacted change, and in order to enact change in mental health care, and also in humanity and dignity and all of those sorts of things, they look to a movement that they saw was able to do it successfully, to some extent.

There's kudos to that, but at the same time – again I'm going to say something that probably is not going to be received very positively by many people, but when I look at our consumer leaders, I don't see anybody who looks like me. So they want to talk about the Civil Rights Movement, but they haven't even included the people who look like me. Like, what is *that*? I don't understand that.

And then when we try to be at the table and talk about these things in the way that we understand them, we're not accepted at the table, which is hard for me, then, when they want to talk about the Civil Rights Movement and bring up Martin Luther King and Bobby Seale and Huey Newton [Seale and Newton co-founded the Black Panther Party], and bring up all these names but don't even look around and see, well, do people who look like those guys – are they even there? They're not. So for me it's hard. I have to admit, it's very, very hard to just give it lip service. I hope that's not—(she laughs) I know people are going to see this or hear this, whatever, and kind of go, “My God, she's so harsh.” I feel harsh. I feel horrible when I do that. I feel horrible.

We're actually reading Judi Chamberlin's book [*On Our Own: Patient-Controlled Alternatives to the Mental Health System*, 1979] now, here at work. We consider her the grandmother or mother of the consumer movement [refers to consumers/survivors and ex-patients who organize and fight for their civil rights], and in her book she talks a lot about the Civil Rights Movement, and so forth, and how this is based on the Civil Rights Movement. I was lucky enough to meet her just this past year before she passed away. We didn't talk much about that because we all knew that she was kind of in her last days. I wasn't going to bring up anything.

But I did think it was important for us as a staff to read the book, to understand what is the genesis of the movement, what is the history of it, where are we now and where are we going. We can't go anywhere if we don't understand where we've been. And nobody in the office had read the book (she chuckles), so I thought, well, maybe we better read it and have some discussion about it. And we're a very multicultural staff, very multicultural. It's been interesting to hear how they're processing the book and understanding related to the Civil Rights Movement. And recognizing, too, that we have Latina and Asian, and they're not seeing themselves, kind of, in the movement, but there's this movement and sometimes they're having a hard time equating how it all fits together.

Again, I think if you look at life cycles of movements, we're in a very interesting sort of growth spurt, where we're kind of a little stuck but we're going to move forward – where our older leaders, too, are coming from a very different – very, very, very different – time. I keep telling people we would not be sitting here if it weren't for people like Judi Chamberlin, and so forth, where in her day they didn't tell you what medications you were taking, they just shoved them down your throat – literally. There was no dignity. You used the showers naked in front of a group of people with nurses and stuff looking at you. When you're in a locked facility you can't even use the bathroom because you're locked out of the bathroom. But if you pee on the floor, then you're seen as symptomatic. (chuckling) The whole thing was like, you know, there was no informed consent [a process in which potential research subjects sign a form, thereby acknowledging that they understand their rights and agree to participate], there was no HIPAA [1996 Health Insurance Portability and Accountability Act, which, among its other provisions, protects research participants’ health information], and because of people like them we do have a lot of protections, but we can't rest on their laurels and say everything is okay today, because it's not. And how much further we still have to go.

V. Cultural Competency/Relevancy; Assessing Cultural Competency; Translation and Language Issues

TG: Yeah. Can you talk a little bit about how you've addressed cultural competence – I've also heard it called cultural proficiency – in your work at NAMI and with Project Return?

KM: Yeah. I call it cultural relevancy. I don't know, I think it's kind of hard to be proficient in lots of different cultures. I'll just talk [about] here [Project Return] because it's more to mind, then I'll go back to NAMI. As I said, before I even came here, it's probably one of the most diverse places I've ever worked. If you see hundred of us – a hundred and twenty, maybe, of us – not here in this office. This is our headquarters. But when we get all of us together, our facilitators and everything and you look at us, I mean, it's amazing how culturally diverse we are – African American, Latino, Asian, white. It's really amazing. Probably where we struggle, which would be a bit expected because of the percentage in L.A., is Native American, but we have a few. Oh, that sounds so token. (they laugh) But we do.

One of the things that we did deliberately this year, and it *was* based on something that I had participated in NAMI a couple of years ago, is being involved with the University of Illinois Chicago on a cultural competency assessment tool for peer-run organizations. Judith Cook [a psychiatry professor at the University of Illinois at Chicago] was initially devising this assessment tool, came to Alternatives conference [the oldest gathering/conference of Peer Advocates from around the country] a couple of years ago and got some feedback about, you know, what does recovery look like for people of color? and so forth and so on, lots of different questions. They devised a tool, then they sent the tool out to be reviewed by peers for any kind of feedback. And I was one of the people who read the tool and gave feedback. Then when I came here, lo and behold, they're looking for sites to test the tool. I thought, well, if it's not a conflict – I don't remember what feedback I gave or not because that was several years ago – we'd be more than happy to test the tool here because we provide services to a very diverse population also in L.A. County.

So we were one of the pilot sites for testing this tool, and we had to come up with a— first you had to assess your organization in relation to cultural competency. The only reason I don't like that term is competency seems to me to be binary – either you have it or you don't – where I think of it more as a continuum. You kind of learn about it as you go along and you learn more and more and more. There is no either/or kind of thing with it.

TG: [It's not] "You are now competent," right?

KM: Yeah, competent with a mental health person term doesn't work for me either. "Oh, you're competent to stand trial." I don't know.

But anyway, we assess our organization where we are, get our mission statement, have verbiage in it that correlated to respecting diversity, that kind of thing. So what about our policies, what about our hiring practices? You look at every layer of the organization and you rate yourself. We had a committee that did this. Then, based on that rating, the tool gives you suggestions about how to be better. So if you rate a 2 and your goal was to be a 4, what are some of the things that you can do to increase that particular area?

We actually did pretty good. Where we didn't is around certain activities, and dedicated activities, and recognizing cultural diversity, and all sorts of stuff. So this year at our annual picnic, which is a really big event, actually we had a theme – unbeknownst to people because we didn't want it to be kind of like a hammer on their head – but it was sort of a diversity thing in recognizing different cultures.

We had different talent presenting from a guy who was signing to music – sign language. We had an African drum group come in. We had a woman singing in Armenian. She was singing Armenian traditional songs. I opened by welcoming everybody in, like, a gazillion different languages and then inviting them to tell a language that I didn't know or hadn't had on my list, so then they kind of got involved. Then we all had to practice the greeting, that kind of thing.

Our food, though, because (whispers) we didn't have a lot of money (they laugh), our food was traditional food. I mean, it was just like, oh here, here's picnic food. But we always think about how do we be mindful of meeting people where they are, recognizing that culture can have an impact on how they view the world and interact with the world, which is, again, how they may receive or not receive services. We do have a client-run center that's Spanish language – *El Centrito de Apoyo* [The Little Support Center]. There are a lot of things we've had to tweak, that just doesn't work across cultures. We have a Warm Line, which is a non-crisis line, and we have a dedicated Spanish line. Unfortunately, because of our funding and so forth, we do have certain rules we have to follow, but what we found was, you know, for the Latino community—well, first of all, with the name, it was hilarious. So the name of the line was initially called the Friendship Line. It's been that name forever. In Spanish, it's called *Línea de Amistad*. Yeah, *Línea de Amistad* does not translate to Friendship Line. In Spanish it translates to Dating Service. (both laugh) We had [people calling and asking,] "*¿Oh, poca gorda?*" ["Oh, are you chubby?"] They were asking "What do you look like?," "How much do you weigh?," "What color is your hair?" And I was like, what the heck does this have to do with mental health? And so then it's like, "Are you single? What's your number?" So our peers are kind of going, "Are we supposed to answer those questions?" I'm like, "Why are they asking you those questions?" And they said, "Well, *Línea de Amistad*," I'm like, "Well, if you guys knew that, why didn't you tell us? We don't have to call it that." So now we've changed it to *Línea de Apoyo* [translates back to English as Support Line], which is a little more—captures [that] it's a support line. It's the best way we could figure to do it. Because Warm Line – *Linea de Caliente* – that doesn't work. You know what I mean? And there's no [direct translation of Warm Line].

And that's really what we've struggled with, is how do we take our materials and make them accessible to people by not doing direct translation? So we did have a lot of materials out there where we were talking about *consumidores* [literal translation of "consumer" in Spanish], and that has no meaning. So we did have to say *cliente* [client]. And I know the goal is to have people use the term "consumer" because it's empowering, using sort of the consumer-buyer kind of movement language. But to the Latino community, right now it doesn't have any meaning – "What? I'm going to the *tienda*?" I'm going to the store? No, no. So we just said forget it, let's just use *cliente* and educate about *consumidores*. But right now, we use *cliente* because we want the understanding.

So that's what we looked at. We didn't have a term for "peers." People were using the term *pares*, which really means, like, pair of shoes. So all of these kind of things, I said, "I think it's more important that we translate for essence and meaning than translate for trying to empower people in a movement, because if they have no understanding, we're not going to get that movement. You can't talk about consumer movement until they understand what consumers are, and we use language to help them get there.

TG: The empowerment has to derive from the meaning, right?

KM: Yeah. I mean, you know – *consumidores* – say *what*? So I think that's' what we've really done here. In our meetings now, we make sure that information is translated, because we do have monolingual folks coming who are employed by us at the Spanish Language Center. We try to get bilingual, but mainly they understand better when things are translated. So I'm not going to fight it and say, "You've got to speak English." I know they can function in English and do their paperwork in English, but they have a better understanding in their own language.

So we do translation, simultaneous translation in our meetings. There's somebody sitting with our Spanish language group doing the translation of what's going on in the meeting. We try to make sure all our materials are translated, when possible – those sorts of things. And that's the major language thing that we have. We're not dealing with any other languages as of yet, or it hasn't come up.

So the same thing with NAMI, I think, is what we try to do. I've been working with the Multicultural Action Center with NAMI National, and now we have a diversity work group that works specifically with the board, because the Center seemed to be somewhat segregated. It had no power, so great, it was like a lip service thing. We have a Center – (sarcastically) "Ooh, yay," and they can turn out documents, but really, where do they have power to impact what we do at NAMI, impact what we do with our affiliates? What's really cool to see is our affiliates are asking us. NAMI is predominately a white organization, but they're asking us, you know, "We want to outreach to the Spanish [speaking] community, we want to outreach to the Russian community, and we don't know how to do it, and we're looking to you to help us do it." So we have this work group now that reports to the board to help us make wiser decisions around our policies and procedures and programs, to ensure that they have cultural relevancy, competency, proficiency, all those lovely words. So, yeah, that's what I've been doing there.

And there's a Consumer TA Center, which is a technical assistance center funded by SAMHSA [Substance Abuse and Mental Health Services Administration], and NAMI National has the one NAMI Star Center, which is focused also on cultural competency issues.

VI. Defining Recovery; Advocacy and Leadership; System Transformation; Ventura County; Layout and Dynamics at County Clinics

TG: I want to talk about the idea of recovery. I've also heard – I think it was first from Catherine Bond – procovery. First, I guess how you would define recovery and maybe how you would define procovery, if that's a term that you're using.

KM: Procovery is a new term to me, so I can't define it. I'm sorry. I know we have a procovery circle here. (she laughs) It's a very new term. I haven't really read the information. To my understanding, it's professionals who engage in recovery? I don't know. You don't have to answer. I'm still learning on that one. My line about recovery is, ask ten different people and you'll get maybe fifteen different answers. That's recovery. There is no – for me – one definitive answer because it's so individualized that it is the individual's response to the question that defines recovery. That sounds a bit elusive, but I really do think it is – recovery is dependent upon an individual and how they define it.

So how do I define it? It's being able to achieve my goals and dreams in life, having the supports necessary to do that, having lots and lots of information to make informed decisions about my treatment (she chuckles) that also has a place in recovery, if you will. Having access to anything that I decide is treatment, or call treatment – having access to that – and being respected and honored and seen kind of as a whole person. That's *my* definition. Somebody [else] may define it differently.

And also, when I make a choice about something, to have that choice honored. If I make a choice about not taking medication, in the mental health movement, that's pooh-poohed. When my aunt, who was diagnosed with Stage 2 cancer and went through chemo, and it was really hard on her—she's not really my aunt, but she's my cousin, cousin, cousin, cousin kind of thing. But my understanding was it was very hard on her and she made a decision that she did not want to continue with chemotherapy, and that she just wanted to find a natural way that's even better – that kind of stuff – to take care of herself. The doctor said, "You sure you want to do that? I might not advise it. Is that what you want to do?" She said, "Yes, that's what I want to do." Everybody supported her. I say I don't want to take medication and people force me.

So I think being allowed to and honoring a person's choice in what they want in their treatment toolbox and what they don't want in their treatment toolbox – being fully supportive of that. That's what I say about recovery.

TG: I mean, it sounds like it's much—like what you said, that consumers are so diverse. There's no single consumer, right?

KM: Yeah.

TG: So one's definition of recovery would be as diverse as the consumers themselves, right?

KM: Oh, yeah. I do get in a bind a lot of times because people want me to take a particular stance on something. And I'm also a person that, for everything that I want to say no to, I want to provide a yes. For everything that I want to improve, I want to provide a solution. And I have a different kind of advocacy. I'm not sort of the screamer and yeller. I'm a person who sits back a lot and just observes, and sort of observes and digests.

I've got a big stick, (they laugh) but I don't use it all the time [a reference to Theodore Roosevelt's line “Speak softly and carry a big stick”]. I bring it out when I need to bring it out, but for the most part, I'm a quiet, observant sort of advocate, and then when I've got the big stick ready it kind of comes out and I do my thing and then it goes back, and I'm quiet and observant. I think that freaks people out a little bit, because the expectation is, to be an advocate, you have to be very loud, very upfront. And I'm a person who believes leadership is also exhibited when you let other people lead, that you're not always in the forefront, you're sitting back and you let other people lead. So when people ask me to take a stance around anti-psychiatry, anti-medication, I mean, that's [saying] no [to] psychiatry, [saying] no [to] medications, so I'm like, “Yes [to] what? Yes [to] what? You're saying no to something, so what are you saying yes to?”

But I have a hard time with that because for some people, they define their recovery as psychiatry and medication. And my understanding of recovery as set forth by SAMHSA is it's about choice, and if I don't let people have that choice, then I don't think I'm any better than the psychiatrist in the system that forces people. I don't want to become the oppressor, so I have a hard time—and I think people have a hard time with me, kind of, in the recovery movement because I won't say anti-psychiatry, anti-medication. I say more information, more types of treatment, and access to treatment. That's what I'm saying “Yes” to – “Yes, yes, yes, yes” kind of thing, but not “No, no, no.”

I just wish there were more room – and again, I think we're just at this interesting phase in our movement – but I wish there were more room for divergent viewpoints and not everybody having to agree, but it's okay to agree to disagree. And if it's fundamentally different, it's fundamentally different. That person has the right to be fundamentally different, and to recognize that there are lots of different ways to be an advocate, so many different ways to be an advocate and a leader. And again, to me, there isn't one way. I'm hoping our movement kind of grows to sort of recognize that.

TG: That it can be more accommodating of a lot of different ways of doing this.

KM: And a lot of different viewpoints. And that people are coming with different viewpoints because they're coming from different experiences within the mental health system, they're coming at different times. We're seeing more and more young people who are coming into the movement. We're having very different experiences than even I had, than even Judi Chamberlin had, than even Catherine Bond had. It's very different. So fundamentally, for them, some of the arguments are a little off because they didn't experience it.

I think that's what we had happen in our office a little bit, and I thought, maybe we need to read some books that are maybe generational so that we can see kind of how have things changed over time so that by the time somebody else ends up at the table, they have the background of everything else that happened behind them, so when they're hearing things it doesn't sound so, kind of like, “What are they talking about? I'm not all about that.” But maybe if there's an appreciation for, “Wow. They went through that. And look, our system is that way because they went through that and fought against it and helped change things – ” maybe that's what we need in our movement to move forward with a clear understanding of the history and why we are where are today. And we have to kind of continually do that because things are continually changing.

TG: Contextualize it historically.

KM: Oh, yeah. I have a weird way of thinking of things.

TG: I think that can be a very effective way of thinking of things. So, the question I have written is – what is the optimum service model for helping clients move toward recovery? I suspect, hearing what you just said, that you don't necessarily think there is *an* optimum model. Would that be fair?

KM: (she chuckles) That would be fair. I mean, the optimum model would be the model that the person chooses. That's the optimum model. So, how does that work in a global sense? Wow. That's the hard part. That's the hard part (she laughs), is how do you individualize everything when you're talking about a system? It's very, very difficult. There are probably some key things that probably need to be in place. It might be the people in the system and not so much the system. So kind of look at this whole sort of transformation of the system, but there's no transformation of the educational system, so our quote/unquote “licensed and trained providers” are learning the old way when there's now a new way, so they're bringing the same old people into what is supposedly a new system. Help me understand *that*.

So then they're spending a lot of time on training folks, like retraining folks like us around sort of recovery orientation and transformation and all that sort of stuff. I wish, simultaneously, as we're working on our MHSA stuff and creating systems of recovery that we were—because the psychologists and psychiatrists and social workers and MSWs (Masters in Social Work), they're not going anywhere. I mean, they're not going anywhere. But while they are a part of the system, they need to be trained in the new paradigm – this sort of recovery paradigm – now. And the training sites that they have to go to to do their internships and field placement and all of that, they should also have recovery orientation stuff in them so that they're practicing what they're learning in the systems that they're involved in, and then they get employed in the system, and so you're creating this interesting little pipeline and people who are prepared to go into this new recovery paradigm.

I think the system as we see it and as it exists is probably not going to change much. But I would hope that it would be more community-centered, in communities in which people live and work and play and grow, that there would be a lot more acceptance of different ways of understanding one's illness and reacting to it. For me, when I got the diagnosis of schizophrenia, I told them, "Oh yeah, right. You can screw that and stick that where the sun don't shine." And we spent a lot of time arguing about it and it got nobody anywhere except me hospitalized a bunch of times.

So finally, the dynamic, or the paradigm shifted when my doctor said, "Okay. I'm not arguing about this anymore. You don't want to accept the diagnosis, you don't have to. We can call it whatever, but the fact is, you know, what is it that you like to do that you're not able to do right now?" I said, "Well, I like to read." "What's the last thing you read?" And I was like, "What?" The wakeup moment. I'm like, “What?” He's like, "What's the last thing you've read? You haven't talked about a good book or an article or anything."

So we talked more about the things I really loved doing that I couldn't do and what was getting in the way of that. And I got to call it what I wanted to call it. "Well, you know, I just can't focus. There's lots of things going on in my head," which really meant, “Okay, yeah. I'm hearing voices, and there's no way I can read when voices are talking to me." But I didn't have to say it that way. I was able to say, "Well, you know, I can't read because there's too much going on in my head and it's too confusing and I can't concentrate."

"So what do you want to do about that? What can we do?" And I said, "Well, let's see if we can read now." And we tried to read together, and I couldn't do it. We came up with some other strategies, but the cool thing was we came up with them together. It wasn't him sitting across the table telling me what to do based on something out of a book. And it was just a different way of conceptualizing what we were doing.

I think we get kind of co-opted in a system of trying to make people—this is a big NAMI thing, and I know I'm on the National Board, and I'm just going to say it. You get co-opted in thinking the path to the recovery is accepting the illness. I never accepted it. I don't care what you—you can call it whatever you call it. I get it. It's about billing. Write it on a piece of paper, bill, and do what you gotta do, but I don't have to believe it, I don't have to accept it. What I understand now is things will get in the way of me being able to do what I really like to do. *Now* what do I do about it? Where are my supports? What's in my little toolbox and what am I going to pull out? How many tools *am* I going to pull out, because maybe one ain't going to do it, so maybe I need a few more.

But I think we really get locked into [the view that] the person's never going to get better till they accept their illness, and they're not going to accept their illness until they're medicated. It just seems to be really—it's not working, obviously. It's a model, to me, that doesn't seem to be working, so how do we allow—I guess what I'm saying about the system is, how do we allow for a lot, lot, lot more creativity around how to address people, how to work with people. That's a really vague answer, but it's the best I can articulate.

TG: It sounds like you're saying a much more holistic approach.

KM: Well, a holistic approach and—yeah, I guess a holistic approach. If I had to say one thing about the system, especially in L.A. because I haven't been inside many mental health centers outside of L.A. County and Ventura—so Ventura does not look like this, it has a different dynamic, which is just as bad. [In] L.A. County, as you go into the clinics, the first thing you walk into is a bunch of signs about guns and weapons, you walk through a metal detector and a bunch of guards. So did I just go into a jail, or did I just go into a treatment center?

I think recovery, too, is about how do you make a facility itself look recovered from the minute you walk into it to the minute that you walk out of it? And I was pretty horrified at some of the facilities that I went into. There was nothing that would make me want to go there. I mean, they search your purse, they make you walk through a metal detector. One of them didn't have a metal detector, so the guy makes you turn your back and he scans you with a wand. Tell me how you're supposed to have somebody who is experiencing a different reality turn their back on you. That's oxymoronic right there. It's contradictory right there, that now you've taken in a person who is not experiencing the world in the way that you are, you have them turn their back on you, and then when they go off and become paranoid, now you're saying they're symptomatic. Well, yeah, you're behind them, they can't see you. They can't see what you're doing. They don't have any visual to help with what's going on. I don't get it.

Again, I just wish things were different. I mean, it's a pipedream. But I feel sorry, too, for the providers. One place didn't have any windows. It had a ceiling like this. I don't know what you call these things on the ceiling, these tile things. But it was very low. It obviously had a lot of water damage, and the rug had a lot of water damage, and the place smelled bad. And it wasn't the people. It was the mildew from the ceiling and the floor. I thought, how can somebody who has to come here every day – from the receptionist to the providers – how do they stay well? It would be great if our system just valued wellness, for everybody, even [for] the people who have to work there.

TG: I do want to get the MHSA, especially since you mentioned wellness again. Before that, you mentioned Ventura County a minute ago. And I'm wondering how you saw—

KM: Ventura different?

TG: Yeah, the [difference in the] mental health care system there from what you experienced in L.A. County.

KM: Well, first of all, Ventura is much smaller, so they only have, like, five clinics in the whole place, in sort of these regional areas, Ventura County, or cities, or whatever they were. So, first of all, the difference is you don't walk through these metal detectors. It wasn't that. It was much more open. I think they didn't—again, not to dash Ventura County because they're working very hard, and when I was there – really, really working very hard, especially their leadership from the very, very top, on inculcating a sort of recovery paradigm in what they're doing. So I have to give them lots of credit because they've gotten a lot, a lot of pushback from folks who have been working in the system for quite some time. I just want to say that because it's really how I feel about it.

But one of the things that they came up against is there is this safety thing, I think, that we all are talking about. In L.A., it looks different. We've got the guards and the stuff. In Ventura County, they lock everything. So you come in, you're coming to your appointment, you can't get to the bathroom, you can't get to water, you can't get to a snack machine, because everything is behind locked doors, and you're kind of out there as a client.

And they say it's a safety thing, and I'm like, I get it, it's a safety thing, but then how does that translate into what I am experiencing as the client, and how I interpret how you think about me? So now you've told me you all are safe behind there, however, I'm not safe out here and you don't give a poop about it because you've left me out here. And you've given me permission to act out. You've given me total permission to do things that I would not normally do in public, that I know are not okay, because you've put me out here and said you expect it of me. So it's kind of like an expectancy theory. You expect me to be violent, you expect me to go off, you expect me to do lots of things, you've put me out here with the expectation – ah, great, now you've given me permission to do it. I mean, (she laughs) that's another classic social theory thing.

My cousin is deaf and they put her in a school for people who are mentally retarded, and they did not know she was deaf. She would get in trouble for doing things because she knew how to do them, because she was not developmentally delayed. At that time they called it mentally retarded. And she would get in trouble, so she was able to visually pick up that what she needed to do was to act like the other kids in the school, which meant that she was supposed to act like she was developmentally delayed so she didn't get in trouble. This is classic. It happens all the time like that.

But anyhow – so I think that was the difference in Ventura County. It was kind of like lockdown. And when the consumers had really come together and said, “We want the bathrooms unlocked, we want access to the bathroom just like anybody else, when we go to the bathroom, men or women, we just want to be able to get in the bathroom or get a drink of water or go to the snack machine. They were told, “Oh, it's for your own protection. Juvenile Justice is just around the corner, people who have criminal records – they're around the corner.” It's kind of what they were always told. And it's like, “Well, people with criminal records are sitting right next to you – I mean, [given] the prevalence of people with mental illness having a criminal record because of lack of access to correct care. So they were – how do you say – told a little white lie, or something? I think that's the difference.

And there wasn't much thought about transportation, [about] how do people get to a clinic? Transportation is a problem out there, so they did have to spend a lot of money on a fleet of cars and vans and stuff to get people to clinics and treatment.

VII. MHSA Programs; Stakeholder Process; Accountability; Racial and Ethnic Mandate of MHSA; Sociological Issues

TG: [pause] Okay. So, what have been the impacts of the MHSA that you've seen? Starting with the good, and if there have been maybe some unintended consequences or bad things that you've seen from it as well.

KM: I definitely think people have more access to different kinds of care. For example, if a person is wanting to be in a peer support group, now we have them. Before, I think peer support was probably mainly in—I mean, Project Return's been around before MHSA, but the other type of peer support that people understood was 12-step recovery [the model used by Alcoholics Anonymous and other groups] kind of peer support. I don't know how long DBSA [Depression and Bipolar Support Alliance] has been around, but I don't think they have a very big foothold in Los Angeles County, so I don't know that there were many DBSA groups within the public mental health system. I see them more existing outside for people with private insurance than within the public mental health system.

So I think peer support. I think definitely programs that address homelessness – not as many, but definitely some things addressing homelessness. Some programs that are working with clients on their goals and dreams and not so much focusing on their illness, and helping them to achieve their goals and dreams, and things like that.

Let's see. What else? Gee, I wish I could say more. (she chuckles) And I mean, definitely, it [MHSA] funds Project Return. But we had a different kind of funding before that was not secure. Talk about mental health care, and one of the sad things about California is the way it is funded, primarily before MHSA, which is sort of general funds [of the State budget] and Realignment [1991 legislation that added a new revenue stream to fund local mental health programs] funding, which means it can be cut or moved around, and that means you never know when it's going to be year to year, which is the way Project Return existed before.

So Mental Health Services Act funds are a bit more secure. (chuckling) A bit more secure. And allowed Project Return, I think, to grow even bigger and add more services that we didn't have before, provide trainings that we didn't have before, and that sort of thing. I think creating a well-trained, or more trained, sort of peer advocate workforce – this is probably new. I think the Wellness Centers [a program funded by the MHSA] – again, everything is a half of this—how do you say it? Sorry, my U.S. [English] sometimes—six of one, half a dozen of the other? Is that it? So it's kind of saying, on the one hand this has worked really well, and on the other hand, [it has not].

The Wellness Centers were initially supposed to be peer-run, but it ended up being fifty-fifty, which is okay. I'd rather that they be there than not be there, even in their existence as peers integrated in with professional staff, which give people, again, access to conceptualizing treatment in different ways. It's not always about the psychiatrist visit, the psychologist visit, it can be about socialization groups, it can be about process groups, it can be about integrating back into the community through community-based activities, it can be yoga, it can be those sorts of things.

I think those are good things because it means that we are starting to think more broadly around what can be in a person's treatment plan. It's been pretty narrow. I think it's starting to get a little bit more broad. And the bad things? (chuckles) The list is shorter. (both laugh)

So, I don't know, I think, at least as I see it in L.A. County, that the Stakeholder Process [the process in which the County designed its implementation of MHSA funds] was a bit unwieldy, which is not a surprise. I mean, we're so big, so big. How could you get every stakeholder at the table? I would have loved to have seen – and still would hope to see – more training about how to be an effective stakeholder. You're asked to come to the table because you represent something, but you're not given a lot of information about how can you exist at that table in the most effective way? If you're going to participate in the process, how can you participate in the process in the most effective way? So I wish some of the money maybe had been set aside for some dedicated training around what is the stakeholder process, what does it mean, if you're a member of the public, how can you use that time effectively, that kind of stuff. What are the expectations? Those were some of the things.

And quite frankly, I don't like the way the room is set up [at the Stakeholder meetings]. It's very hierarchal. “Delegates sit here, and alternates sit here, and the public sits here.” And it's kind of very, you know, “The public doesn't speak unless they do it through their delegate.” I get [that] there needs to be a sense of control and a sense of process. I wish it had felt a little bit more egalitarian. It felt very hierarchal, which maybe flies in the face of transformation, I don't know. But I didn't come up with another solution. I was in the process really late. So it is what it is.

But as far as some of the care stuff and the money stuff, I think—I do wish that the funding were—I wish L.A. trusted that peers really do have something to offer. I don’t think we’re trusted. You hear a lot in the stakeholder meeting. And I think because, again, there was no training in how to be an effective stakeholder, in lots of different ways. I'm not saying it has to be *the* way, but in lots of different ways that it was generalization about abilities of peers and what they could do based on what they were seeing at the stakeholders meeting, which is sad because those are their providers. [I’m] generalizing.

So, have we gotten anywhere? Probably not. And I'm being cynical, but I worry that—here is an example of how Ventura and L.A. are very alike – and I wouldn't doubt other places are very alike [in this way too] – is that, for the most part, our Department[s] of Mental Health, the public ones, are working with – especially those that have been in the system because that's what's been happening and why we're talking about transformation – is people are rolling around in the system. They're not graduating up and out of the system. They, for the most part, stay in the system and never move out, always receiving services and never move out.

So, on some level, what L.A. County and, say, Ventura have seen are what we would say – again, it's not very consumer language, but it's the easiest for me just to say it – sort of the sickest of the sick. And to imagine that that person you [a provider] have been seeing for 15 years is now going to run a support group, I get it. That would be a little foreign. Like, “Okay, wait. I can't even get the person to take a bath, and now you want that person to run a support group.” That's how they're interpreting this, but that's not what we're saying. And I think, again, it's a generalization that [from a provider’s perspective], “The people that I see on my caseload are mental health consumers, in general. And the idea of that person working, holding down a job, providing services to another person? [She gasps] It's not going to happen.”

So that's where they take in their world view and put it on all consumers in L.A. County. And if somebody says something in a meeting – it could be me, it could be another executive director of another program, it could be the L.A. [County] Client Coalition [organization of Los Angeles County client/consumer mental health advocates] chair, it could be anybody – if we say something that seems a little off, [people think], “Aha, it's because they're a consumer.” No, it’s just because I said it [not because I am a consumer].

I think that's been sort of a sad consequence of this whole thing, is that I don't know that we've transformed anything. Otherwise, I don't think we would have people at the table sitting, thinking that consumers don't have the ability and can't be trusted in a work environment to provide services. I do know that's the undertone, for the most part, and I do understand why it exists, but it saddens me that we're still there. We have a lot of work to do around that.

And then the only other thing is that, you know, we've rested our laurels on this Mental Health Services Act. We're seeing it now every year when there’s a budget problem, the governor kind of goes after it and tries to supplant. Now he’s wised up and he's actually using the word "supplant," so he's wised up and said, "Yeah, that's what I'm doing. Okay, I'm going to admit it, and now I'm going to see if we can get whatever they call it passed so that we can vote on it in June." And the word [supplant] is in there.

But I think the bigger issue for me is, it's an Act. Can an Act be repealed? I never felt safe about this thing. I've always felt that, particularly if we are not reporting a variety of outcomes – and outcomes could be on many different things – but if we're not reporting our outcomes and how we are using the money, and that the money has impacted change and a difference in people's lives, and outcomes of what we wanted to see, which is people sort of graduating up and through the system. If I were a millionaire, I'd say, "Quit taking my money" [a reference to the 1% tax on millionaires in California, which funds the MHSA]. And I might find a legislator and say to that legislator, "I don't want them taking my money anymore because they're not using it wisely, and I have a problem with that." I might say that if I were a millionaire. I mean, I wouldn't say it now, but it's all very hypothetical.

So, my worry has been, how do we be – it's almost like being on a board – “How do we be fiduciarily responsible for the money that's been given us?” (laughs) That's what I feel like. How do we be fiduciarily responsible for these people's money, and how do we report to them, “Hey, thanks for giving us one percent of your million, and by the way, this is what we did with it, this is how lives have been changed, this is how people have been impacted, this is how actually, now, these lives are giving back into the tax base. This is what has happened with your money.” So that maybe they can feel comfortable about giving money to something that they did not choose 100 percent. Do you know what I mean?

TG: Sure.

KM: I think that's been my other disappointment, is about—and this is not a treatment one, but this is more around how we've been responsible with the money and how have we reported that to the public, to the State, to California residents. I think they deserve it, and I think we could be better at it. Those are sort of my biggies, a little bit.

TG: I know one of the mandates when it [the MHSA] was passed was to address racial and ethnic disparities in mental health care. And I wonder if you think that’s happened.

KM: Jiminies. Okay, well, hmm, hmm. I guess my best answer is I don't know. I don't know. I know in my little corner of the world what we have worked very hard on doing – and I see a difference in the numbers, too, so I don't—anybody else can do what they want to do out there. And I'm not driven by numbers without attaching it to people and stories, so I'm a qualitative, quantitative person. I think both have extreme value in how you understand what your organization is doing, how you report on your organization in measurement. It's not just about a raw number. There are impactful stories behind those numbers that are very important to capture, too, and report on.

I still think sometimes, especially when I hear language that kind of—I have to go, “Huh?” I just have this moment of, wow, that *so* didn't sit right with me. But there was a time – and we had to work very hard on it – when they were calling African Americans “high users of mental health services,” which, yeah, that makes me want to go back to my therapist tomorrow. You've just now identified me as somebody who is basically using more than my fair share. That's what that term meant, is “You're using more than you're really allotted,” and they attributed it to African Americans.

And I thought, well, doesn't that tell you something? Versus it being a negative thing. So numbers, to me, are intriguing because there's a story behind it. What's the story? Initially, the story was, “Reduce the services that they’re [African Americans are] using.” That was the story – “They're higher users. Reduce the amount of time they're using services or amount of services they're using to get them kind of more in line with population numbers and all that kind of stuff.” And I said, "Well, that's a really easy answer, but to me, there's a bigger story around why are African Americans high users of service?" To me, if somebody is using a service over and over and over and over and over again, and the outcome is no different, then something's the matter with the service, maybe.

So what is that telling us about the service and African Americans? Is it [the service] culturally relevant? Are they even receiving services? My understanding, when we really did kind of did get into it, was people were signing into the clinic, [getting] frustrated with waiting, and [leaving], but they counted it as using a service that day. Those sorts of things. So we had to fight really hard to get the term "high user" removed, and it was changed to something else. I don't remember what it is now. But people kept really shrugging it off, like, “Oh, it's no big deal to call it a high user.” And there was no appreciation for the fact that, yeah, it is a big deal. We don't like it, don't use it. It might be the reality of the situation, but it's seriously not *capturing* the reality of the situation.

That's why I sometimes wonder if there's a true appreciation for some of the cultural competency stuff. I think it's understood [in some ways, such as with] language – translate stuff. But I think some of the dynamics kind of haven't been understood or addressed very well. I don't think I see anything different in how African Americans as a whole are receiving services in the County. They're the same old services delivered in the same old way, so how is that culturally competent? I don't know.

There is now in the South Central area a Pearl Ella Johnson Wellness Center, which is set up to meet the needs of the African American community. [Pearl Johnson was a prominent speaker and mental health advocate in L.A.] But it's still getting off the ground, so I really can't comment on how things are going there.

But I think in other ways, they've done very well. I think it’s maybe some of the more long-standing communities are having a little bit more difficulty trying to—and it might be putting a square peg in a round hole. There's a book out just recently about this guy from—I think he's from Yale. The book is titled *Schizophrenia: the Politicalization of Black Madness*, or something. I don't know, something like that. And he's making a compelling point that the misdiagnosis of African Americans, especially African American men with schizophrenia, at a time when there was a lot of fear about African American men in power, so back in the Sixties, and so forth. During the Civil Rights Movement, people were diagnosing African American men left and right with schizophrenia and locking them up. What a great way to control a group of people.

I was reading another book which is based on an exhibit that went around called Suitcases From the Hospital, or Suitcases From the State Hospital [“The Lives They Left Behind: Suitcases from a State Hospital Attic”]. I'm sorry. I'm not very good at doing stuff off the top of my head like that. What they were talking about was how when people went into state hospitals, they sort of lost their identity, but they have one and it was in the luggage that they brought that was put upstairs and locked up in the lock spaces of the hospital.

And at state hospitals that have been closing or doing memorial projects, they're finding these suitcases and they match the suitcase with their charts. And when immigration was an issue – and this was back in the thirties, forties, whatever – a lot of people who were immigrating to the U.S. and had poor language skills were institutionalized in state hospitals – like, forever. They would open the suitcase and they would find the person in the suitcase. It wouldn't be number 1225B, it would actually be the person, and the case file would say how this person had no connection to family, but they would open the suitcase and there were pictures of their family and mementoes of the family and things like that. The case file would say, “Oh, they have no connection to their family.”

I remember particularly this one woman from Austria or Germany or something, I can't remember, had limited English and they were writing how actually she was a model [patient]. Finally, one person wrote, “I don't understand why she's here. She's a model patient, she's a model person. I don't understand why she's in a state hospital, other than she doesn't speak English very well.” (she chuckles)

I guess what I'm getting at is – what of certain cultures’ issues are really mental, and what are sociological? And have we become trapped in the system because we're dealing with a society that we're still not a majority in and really struggle in, yet now we're trapped in the mental health system, which is not really where we belong, and maybe that's why we're really high users. I think that's kind of the argument this guy was sort of making his – you know, that kind of stuff.

I think we could do a lot better around some of the cultural competency issues and move it beyond the obvious of translation and that sort of stuff.

VIII. Peer Support; Stakeholder Process; Field Services

TG: Moving now—this may include MHSA too, but not necessarily. In the time that you've been in L.A., what, for you, has been the most important change or development that you've seen happen with mental health services?

KM: (pause) I guess that places like Project Return or here, places that provide sort of that been there, done that experience for people so that what can be sort of an unequalizing, scary thing can now be put in the context of, “I'm not alone,” kind of thing. For me, that's the biggest thing. I think that's the biggest thing. You know, when I was first hospitalized, when the patients would talk to each other and try to support each other, the mantra [from hospital staff] was, “Work on yourself, don't work on other people. Work on yourself, don't work on other people.”

And again, what was being shut down was a very natural process of peer support. It happens in physical hospitals. When you go into the hospital for a physical ailment, you're generally talking to your roommate, and you're sort of commiserating around different things and providing each other support. And nobody says anything about it. They want you to be there to support each other, as a matter of fact. You have a similar illness – breast cancer or something – it's lauded that you go to the support group. It's actually *recommended* that you go to a support group to talk to people who are like you.

However, I think in the mental health field, that's not happened, and wasn't happening. It wasn't happening at the time that I was hospitalized many times, and now it's encouraged. So I think that's probably—the biggest thing is recognizing that peer support does help, it's valuable, and it's a natural process, and allowing people to have access to that process. I think that's the biggest thing.

TG: What has been—we ask if it's your biggest disappointment or something that you really would have liked to have seen happen that hasn't. I know you've kind of addressed this in various ways, but if there's maybe something that sticks out, or if it's a few things. And that could be in L.A. County specifically, or just in your time working in mental health. I know that’s pretty broad.

KM: Yeah, it is. Wow, one thing. I will say this. I wish we were a lot further along with MHSA funding. I get the stakeholder process, but the whole thing just seemed unwieldy. We never know where the money is, and it stays up at the state forever, and la de dah de dah, it finally makes its way down here and then you have more processes about how to distribute it, and, oh my God, I mean, I'm sorry, people are dying while we're doing all this crap.

I mean, I think that's the most disappointing thing to me is that, for me, there's a sense of urgency around people's lives and people's wellbeing. And I know we exist in a red tape system, but I really wish we could figure a way to manage that so that we can impact more lives more quickly, and kind of do it in a—you know, parts of the MHSA plan that feel very guinea piggish to me, and probably Innovations [the name of the final plan outlining the use of MHSA funds in L.A. County] is going to be the most of that we have to get comfortable with. I get very uncomfortable when we have to try things out on people to see if they work. And sometimes that gets people's expectations up and then they get dashed. Or it gets people's expectations up and [people say], “Look, it's a great thing,” and it becomes sort of more widespread. But my initial reaction is, oh, it's going to be a trial thing. I’m going to feel bad for people if we do something and then we have to think it.

I just wish we had access to the funding to make a greater impact on more people's lives. And that more of it went to, I guess, the community rather than to – this is going to sound so wrong – but I wish not so much of it went to DMH to manage the process. Because there was a lot of the money—immediately there was money chopped off to manage the process of the stakeholder bit, to pay the consultant, to pay for the room, to pay for the food, to pay for all of these things, to pay people's salaries, and so forth. I wish we didn't use so much of the money to do that, that maybe we had found different ways to do the same thing using less of the money that could have, again, impacted people's lives.

I definitely wish we had looked at meetings in which parents with children [with mental illness] could have attended. I think we missed the whole stakeholder population of—yeah, they have a representative there, but really, why didn't we have some meetings in the evenings where people who work, of our public community, could have been more involved, and if they needed childcare, that we were some place where we could have had some childcare.

And looked at some models in—it was either Australia or New Zealand, or both, about how they had the very, very same issue. They have a process very similar to ours, and they did have to tweak it to ensure that it was capturing as many stakeholders as possible. And I don't think we've done that. I think it's been very comfortable for the meetings to occur when and near DMH. I'm a horrible person for talking about the people who pay me. I really am. I feel horrible, but I really do wish we had thought about, hey, how can we make—there've gotta be ways. And there were some focus groups and things when certain plans came up – but consistent ways for [there to be] involvement of particular groups, I wish it had happened differently.

TG: That it could have been more accommodating to more people?

KM: Yeah. You know, I feel so sorry – [saying] “I feel so sorry,” it feels like I'm being empathetic. But Antelope Valley. Do you know how far Antelope Valley is? And they have to schlep all the way into L.A. Why? Why couldn't we have one meeting where we schlep all the way out to Antelope Valley? I've done some presentations out there, and it's just like, you've gotta be kidding me. I mean, this place is like—it's deserty and—I mean, it has everything in it (she chuckles), but it's out there. And how have we made it accessible for folks in that region to be involved in the process? The meetings were always kind of near DMH on Vermont somewhere at a hotel or [other place]. How could we have had them in different areas, and again, gotten consumers there, and people have transportation issues, and so forth. That's the part I kind of wish had been done differently.

I forgot what the question was. I kind of got my head wrapped around that. What was the question? Was that the question about the MHSA process or about the mental health? I'm sorry.

TG: No, that's okay. That was about just—let's see. What was that?

KM: (She laughs) Sorry.

TG: No, no, no. That's totally fine. I think that was about something that you would have liked to have seen done that wasn't.

KM: Okay. The only other thing is – so if it's about mental health services – and I [talked] about the [Mental Health] Services Act. I'm done with that. [If] it's about mental health services, I wish we could do more around outreach and providing services directly in the community, not making the community come to us. If that means people who – a group of people, two people, whatever – who go to someone's home, who meet somebody in a park, who meet somebody at their church, whatever. How could we have been more mobile and done things where people are, or where people want to meet us? There's some communities where [people say] "And don't come to my door. I did not want them to know that I have a mental health issue." So we have to be mindful of that. "So where *do* you want to meet us? Where can we be where you feel safe and know that you're not going to be quote/unquote 'outed'." And now I'm talking about cultural reasons why people do that. So I think those are the two that I wish were a little different.

VIV. Accomplishments at Project Return and NAMI; NAMI National Board; Medication and Treatment

TG: What do you consider your most important achievement, or something that you're particularly proud of that you've gotten to be a part of, or oversee?

KM: Oh, shoot. Here – Project Return. Well, I probably have two. I have two. I think—I'm probably going to cry because my mom just passed away, but she wanted me to be very happy in my job. She saw me struggling before, and hospitalized, and so forth, and my different—and my career in admissions. She never got to see me as happy as I am, because I love my job here. So I would say that.

And I love it here because the people I work with are just so incredible and just so, so amazing. I just feel lucky every day that I get to come and be around people that I totally respect and like, and I get to see them. I mean, when I see a spark go off in their eye when they've learned something new, or they're using a new skill, or growing in their job. We do have people who decide, "This isn't for me. I want to go off and do something else." And so they resign. Even that is—it's a great moment because people are now starting to process who they are and where they belong and how they can achieve what it is they want to achieve. I mean, to be a part of that is incredibly humbling and—I don't know. It's just amazing. So I think that's the biggest achievement. One of the biggest.

And then I think the other is – I was kind of a long shot to get on the NAMI National Board. I don't think many people may know this, but to get on the NAMI National Board was a defining moment because, first of all, the year that I ran I think there were five seats open and four incumbents. So, traditionally and historically in NAMI when there is an incumbent, they get in [given] the way that NAMI voters vote. If you're incumbent, you got in. No brainer. So, technically, there was one seat left amongst about, I believe, three or four of us. I think it was three of us. Maybe four. I can't remember. But of the three or four of us, three of us were consumers. So now we're talking about a family organization and consumers on the board. And still it is kind of [that] they count numbers. “How many [consumers] are there? We don't want another one.” That kind of thing. I mean, I’m being honest.

Of course, I'm the only person of color, so we've got that dynamic and it was like, “Oh, how many of them do we have? No, we don't want another one of those.” And really, this is – I’ve been in the caucuses – these are the questions they ask themselves in order to make decisions. “How many consumers? We don't want another. How many black people? We don't want another. And, by the way, nationally, how many Californians on the board? We don't want another.” So that year, there were already three Californians on the board. So if there couldn't have been more things against—there really couldn't have been.

But the biggest thing against me is that one of the other people who was running, who I thought—when I found out he was running, I was like, who the hell nominated me this year? I'm not going to win against this guy. What are they doing? [It was someone] from the Treatment Advocacy Center, which, for many consumers, is – not all, but for many consumers – we don't really agree with assertive outpatient treatment. We see that as coercive. It's basically—yeah, it's a forced outpatient treatment.
So he was my main opponent, and I'm thinking, well, this is—forget it. This is like, are you kidding me? I'm not going to win against this guy. And he's a New Yorker, and New York is the other big constituency. And there were no New Yorkers on the board, so I thought, this is not going to happen and he's going to win, because this is something that NAMI has really wrapped its head around. It has a policy around assertive outpatient treatment, and so forth. So I thought, I'm not going to win.
When they told me I won I almost fell frickin' over. I was like, "How the hell did I win?" And, of course, he was like, "Recount the votes!" (they laugh) They recounted those suckers many a time, and then they had to verify that everybody—I mean, it was just this nightmare. I mean, this is behind the scenes sort of stuff.

But the reality is that NAMI was sending a clear message – I think – with that. And even though I'll admit it was a slim win—I don't know the numbers, but my understanding was that it was not an overwhelming—it was [a] pretty nice margin, but not like, woo-oo. But it was a clear message that perhaps NAMI is now really wrapping its head around what does it mean to have access to treatment, and what does it mean to sort of conceptualize mental health treatment as sort of this continuum, and that we spend a lot of our time in NAMI down here around reduction of criminalization [of people with mental illness], which is an issue.
And it's a big issue, and I'm not saying it's not a big issue. We talk a lot here around medication and research and having better medications so that we don't have metabolic

syndrome [a collection of risk factors that increase a person's chances of having certain health problems]. It's kind of a new move for NAMI. It used to be, “Just give them the medication and shut up.” So now we're talking about, “Great. We recognize medication can cause other side effects that are really quite deadly,” if you want to focus on that.

But now we're talking about, “What if you don't have access to any treatment at all? The likelihood that you're going to end up here is far greater.” So now they want to have this discussion, I think, about, well, wait. Maybe the discussion isn't about that assistive or assertive outpatient treatment as the answer, that everything is not a nail. You've got screws and bolts and – I don't know – lots of different things, so maybe we need to address them in lots of different ways. So I think they were saying, “Maybe it isn't always about this, and some of us are really kind of uncomfortable with this and we want to start having a dialog in a different way.”

So now that I'm sitting on the board, and I'm on the Executive Committee, is like, whoa! I mean, it's a huge achievement, but I think how I perceive it is it's NAMI's growth and movement, in lots of ways. And they did question me up and down about coming from California, and they did bring up the other black person who was from California. So they were also talking about another black – “And what about Marty?” and they were talking about the consumers on the board, and they were able to say, “Look. A view is a view is a view is a view.” That's pretty cool.

So I think those two things. And when I walk across the stage to get my Ph.D., that'll be the other one. That's it.

TG: Those are all the questions I have. Is there anything else you would like to add or like to say that I didn't ask?

KM: No, I don't think so. I think that kind of covers it.

TG: Okay. Well, thank you so much.

KM: Oh, you're welcome. Thank you. I hope it's helpful.

TG: Absolutely.

END OF INTERVIEW