

### **Mariko Okumoto describes finding the right treatment...**

I didn't know what [schizophrenia] was, and I was kind of [angry] – “Why did they put [me] in the hospital? Why wouldn't they just let me go and let me alone?” But then after several years I spent going in and out of the hospital – maybe four or five times – the doctor at Harbor-UCLA told me, “Try going to the Coastal Asian Pacific Mental Health Center of Gardena. You're Asian, so try to go to this Asian center to start it. Maybe they can help you.” So, I started there. Took a long time – took 25 years. Twenty-five years, but they finally found the right medication, the right dosage, the right therapist and everything...

[The Asian Center] knew the culture. They knew the culture of the Asian. They knew their system and the rules of the Asian ancestors and things like that. That's the way they covered that. They didn't say that was the wrong, they just followed it and accepted it and let you know why you should change it maybe, or expect to change it a little.

**READ THE FULL TRANSCRIPT BELOW.**

**Interviewee:** MARIKO OKUMOTO

**Interviewer:** Katie Cadigan

**Date:** February 5, 2010

**I. Becoming ill; Hospitalization; Coastal Asian Pacific Mental Health Center; On Family**

KC: What happened in your life that brought you to get treatment for mental illness?

MO: When it first started, I was a nurse's aide, and I started getting depressed and hearing voices. I didn't know it at the time. And I started drinking. I was drinking, but still going to work in the morning. So, I was hiding it from everybody, that I was hearing voices and mad. But I got so depressed and so mad, I ended up in the mental hospital.

KC: When you say you were mad, what do you mean by mad?

MO: I was mad at the whole world. Mad at everything that was happening, talking about my parents. I even wanted to kill my parents and things like that. And I felt so embarrassed and so disgusted with myself. I had no self-esteem. I didn't know what I was doing for the life. And I just wanted to just end it.

KC: So, did you make a suicide attempt?

MO: I did, and that was my first time in the hospital.

KC: So, tell me again how you got into the hospital.

MO: I was drinking a lot. And I just tried to cut my wrists, so they put me in a hospital. I was there for three months. And I got worse in the hospital. They gave me the wrong medication – too strong medication because I found that the Asian people are smaller than the Caucasians. And the dose should be lowered. They gave me the regular dose for bigger people, bigger-frame people and things. So, it just affected me the wrong way.

KC: Did you get a diagnosis right away?

MO: I did. They said it was schizophrenia. It was schizophrenia for the very longest time. It's always been schizophrenia, so I think they didn't miss it, didn't make a mistake on that.

KC: They just made a mistake on the medication.

MO: On the medication, it was just too strong.

KC: Now, did you understand, when you went in the hospital, that you had a mental illness or what schizophrenia is? How did you come to understand what schizophrenia is?

MO: I didn't know what it was, and I was kind of mad – "Why did they put [me] in the hospital? Why wouldn't they just let me go and let me alone?" But then after several years I spent

going in and out of the hospital – maybe four or five times – the doctor at Harbor-UCLA told me, “Try going to the Coastal Asian Pacific Mental Health Center of Gardena. You’re Asian, so try to go to this Asian center to start it. Maybe they can help you.” So, I started there. Took a long time – took 25 years. Twenty-five years, but they finally found the right medication, the right dosage, the right therapist and everything.

KC: So, what was different getting treatment at the Asian center than before? What helped?

MO: They knew the culture. They knew the culture of the Asian. They knew their system and the rules of the Asian ancestors and things like that. That’s the way they covered that. They didn’t say that was the wrong, they just followed it and accepted it and let you know why you should change it maybe, or expect to change it a little.

KC: And were there cultural barriers to understanding or to having a mental illness in terms of getting treatment?

MO: It was because it’s kind of a shame to admit it that your family member has an illness. And it’s bad for the ancestors. They think it’s a shame for the ancestors and for the family to admit that the family member has illness.

KC: So, how has your family dealt with it?

MO: **My father used to deny {still denies} it.** He said, “You’re just being lazy. You’ve just been doing it because you wanted to stop working,” and things like that. But my mom understood. She was there from the beginning, and she knows why I tried to commit suicide. It’s kind of hard to explain to my dad. **Sometimes I think {Just starts w/ he}** he still doesn’t accept it.

KC: Do you have brothers or sisters?

MO: I have one younger sister.

KC: And how is she with it?

MO: Right now, she’s okay. But before, she was blaming my parents like I used to – “You’re the one who caused it for her.” But now she kind of understands what’s going on.

KC: So, what do you believe caused it, or what causes schizophrenia?

MO: Schizophrenia, for me, I found out, is a chemical imbalance. Not only chemical imbalance, it could be genetic. But that’s not the only cause. You just may be imbalanced with the chemicals.

## **II. Peer support; Working at Project Return; Understanding Causes of Mental Illness; On Stigma; Mental Health System Today & Reducing Hospitalizations; Closing Thoughts**

KC: What in treatment has worked for you?

MO: The treatment for me, basically, is a combination of a self help group – peer group – plus the clinical medication and staff at the clinics.

KC: So, describe—there are a lot of people who don't know what a peer group or self-help is.

MO: Peer group is with the fellow clients, consumers are—they know what they went through. They can help the other people who are suffering through the same thing. So, we're a self-support group. And we know what it's like to be sick. So, this is what helps us a lot, too. It helps other people.

KC: Give me some examples of things that have happened in the self-help groups that have helped you the most? Is there something somebody else said once that really opened your eyes?

MO: Yeah. This one friend of mine worked for Project Return. She gave me the support and self-confidence to continue to work harder. She said, "No matter what anybody says, you know what your illness is. You have to work on it. No matter what the doctor says, you can do it, and have faith, and try. No matter how long it takes, you can do it." This is what the self-support person told me. So, I live by that, and it took a long time, but I'm there now.

KC: Were there really, let's say, really horrible or wrong things that people told you along the way? Like what she was saying – "regardless of what the doctors said" – were you ever told wrong information?

MO: Basically, I was told by my doctor, maybe after 5 years of treatment: "You will never get back to work. You will never get a relationship. You will not be able to do anything. You cannot handle any stress at all." That is what my doctor told me. [At] the same time, this friend told me, "You can do what ever you want. You can improve, take time, but do it, prove him wrong." See? So, that's a big difference.

KC: So, how have you proved that doctor wrong?

MO: Right now, I still see the same doctor. Yeah, I still see the same doctor. And now he's telling me, "You can do whatever you want. Just don't do too much stress and try to learn how to better control it. But you can do what ever you have to do."

KC: So, what have you done to fulfill what he promised?

MO: Now I have a **very good male friend {boyfriend}**, and I'm working, part-time.

KC: What do you do?

MO: I'm a peer supporter. I work with an organization called Project Return Peer Support Network. And this is, like I said, a peer support organization. All peers.

KC: And what do you do?

MO: I kind of supervise. I'm like a supporter. And I run, I help lead people who run groups. And we have 13 groups, so I am over basically 13 or 12 different people, all with consumers.

KC: And what is a consumer? A lot of people think consumers are people who buy stuff.

MO: What we call consumers are basically people with mental illness – mental disabilities, a mental illness. We call them clients or consumers or crazy people, (laughs) or whatever people want to call them.

KC: What do you think has been the biggest challenge you've overcome during your treatment?

MO: Basically to have more confidence. Knowing I could do it if I really wanted to, and I can help people. And whatever, it's not impossible to improve, to get in the recovery step.

KC: When new clients come in or you're working with someone who's just getting diagnosed and really new to the illness, what do you tell them? What kind of advice do you give?

MO: What I basically tell people is it takes time. It took time to get sick. It didn't take maybe overnight to get sick, so it won't take a miracle to get better at one time. It'll take time. And I just tell them what happened to me – like it took 24 years for me to get diagnosed and really find the right medication. And it took 24 years for me to get the right thing.

KC: Can you describe, again, what was so helpful about getting the Asian support?

MO: Basically, they knew the culture, and they understood how I basically felt. And they could explain it better to my parents because of the language.

KC: So, did they explain it in English?

MO: No. My parents speak Japanese, so they spoke in Japanese. And that's what I found out to be helpful too. If you have counselors or doctors in different cultures, that they can help the people and understand the culture of the consumer, then that would help them to understand the illness better.

KC: You said before that in Japanese culture, there's a lot of shame – like there is in almost every culture – but that it's also a shame on the ancestors. Can you explain that?

MO: Okay, the people in Japan or other Asian countries, they probably feel *they* must have did something bad to make you get sick. The ancestors did something to hurt people or hurt other people to make you get sick.

KC: And do you believe that?

MO: I used to, because I felt really bad and felt really resentful to my ancestors and to my parents.

KC: So, would you say you thought your ancestors and parents had caused your illness?

MO: I used to, yeah.

KC: Describe how you felt.

MO: I felt, why would they let me get this way? Why did they cause it? Why did they let it happen?

KC: When you're working with peers, do you bump into a lot of people who believe that?

MO: They do. They still do.

KC: What do you tell them?

MO: I tell them it may be caused by chemical imbalance, and nobody's to blame. There's no blame, so once you get over the blame, it'll help you to get better.

KC: When you're working with other peers, what do you see are the biggest barriers for people? Other than the self-esteem and belief that you can, are there other barriers to people really getting treatment, or accepting treatment, or accepting their own illness?

MO: There is a stigma. It is kind of hard to admit that you have an illness or to admit that you're working for peers because that lets everybody know you're sick, you have an illness. And it's kind of hard to admit it, so you don't want to tell anybody. So, it's kind of hard to say you're a peer.

KC: How do you do that? Do you tell people in public? When you meet someone, you say hi?

MO: Right now I do. I say I'm a peer supporter. They ask me what kind of supporter, so I tell them, and they say, "That's great. We need a lot more of them, huh?" So, I just say, "Yes, we do need a lot more of them."

KC: In your own life, in your long journey to how well you're doing now, what's some of the worst stigma you've encountered?

MO: Probably something like [people saying] "You're being lazy. You're just crazy. Everything you do is because you're mentally ill." And the stigma now is people who do things wrong are automatically [told], "You're ill. You're mentally ill," [or] "They had a diagnoses," or something like that. That is the worst stigma right now for everybody, even for me.

KC: Do you bump into people who, [when you] say you have schizophrenia, are afraid you'd be violent?

MO: Some of them are. But after a while, they say, "I was scared of you, but I'm not scared of you anymore."

KC: And have you ever been violent?

MO: I get mad a lot. But I've never been violent. I never try to hurt anybody, but I hurt myself. But I don't hurt other people. That's what I want people to know – people with mental illness usually hurt themselves; they don't hurt other people.

KC: What else do you wish the world knew?

MO: That some of the most sensitive people have mental illness. They're not all sick and they don't always commit crimes, and they don't commit murder. Maybe the most crime they do commit is they hurt themselves. They don't love themselves.

KC: If you could change anything in the mental health system, what would you change?

MO: Probably the budget. The budget – they’re trying to cut it. Like the MHSA [Mental Health Services Act, currently the primary source of funding for California mental health services] funding, they’re trying to cut it and take it for other things. My point that I want to say is don’t cut it. To the senators and everybody – don’t cut it because they’re creating more chaos, more problems. They’ll have more people misdiagnosed, more people in the hospital, which is more money. If they want to save money, create more self-help groups or more, better clinics to help the people. Then keep them out of the hospital. It’ll save more money than putting them in the hospital.

KC: My brother once—they wouldn’t allow him to have another medication on Medi-Cal. And so, he got sicker and sicker. The medication would have cost \$250 a month. Instead, he went to the hospital at 5,000 [dollars] a day.

MO: Yeah. See, that’s the point. If you find the right medication, it’s worth it. You stay out of the hospital. Hospital’s maybe 6,000 [dollars] a day now. But medication, at most, maybe costs 300 a month. Isn’t better to spend the money for the medication and have the person back to work?

KC: What do you think of the mental health system today?

MO: It’s not doing its job. Basically it’s not doing its job.

KC: Describe how, why it isn’t.

MO: It isn’t because it’s not open to everybody.

KC: Who is excluded?

MO: A lot of the underserved population is not really served.

KC: Like who?

MO: Like the African-American, the Latino, the Asian-American, all the Indian, Native Americans, and all of the people. Even the people with physical disabilities are being underserved.

KC: What would you recommend for someone’s who’s ill [and] from one of the underserved population as they’re just coming into the mental health system? Do you have advice?

MO: I want them to join. Come out to the General Coalition meeting to speak out and let their issues [be] known. We have a big voice now, in the mental health system. And if they come out and speak, we can gather all the people together and come out and fight back.

KC: And what’s the biggest thing you want to fight back against?

MO: Probably about the stigma. Probably about the lack of—the budget spending more money, keeping them in the hospital instead of spending it for better medication.

KC: Has therapy been helpful for you?

MO: It has been. It’s equal. It’s equal.

KC: Describe what—

MO: Equal because I say medication plus the clinic is the first step, first step to recovery.

KC: What happens in the clinic?

MO: The clinic is they give you purpose. They tell you why mental illness is genetic, why it's a chemical imbalance. They let you know the main, basic reason why it might be started.

KC: And once you knew that, how did that make you feel?

MO: It made me feel I didn't have blame anymore. I didn't have hate for my parents or my ancestors.

KC: Is there anything I haven't asked you that you think I should be asking you or that you would want to tell people?

MO: Not really. I think we covered most of it.

KC: The other thing I was wondering about – is there a number one question that peers or clients ask [that] they are worried about when they come to a peer support group?

MO: They think everything will be talked about, everybody will spread the gossip and talk about what they talk, personally, about. The word of confidentiality.

KC: And what's the truth about confidentiality?

MO: Confidentiality is we don't spread the word. Whatever goes on at the meeting stays at the meeting. We don't even tell the counselors what we talk about. But if they do say, "We want to kill ourselves [or] we want to kill somebody [or] we want to harm somebody," then we have to break the confidentiality rule. But otherwise, everything is confidential. We don't gossip.

KC: Have you ever had to report someone?

MO: I did. But when they put her in the hospital [and] she came out, she said, "Thank you. I couldn't tell my counselor that, but you told her for me, and she got me help."

KC: That's amazing. Okay. Can you tell me, just say in one sentence, what your name is and what your diagnosis is?

MO: Okay. My name is Mariko, and I have schizophrenia.

KC: And now, again, say your name – your first and your last name – your diagnosis, and what your job is.

MO: Okay. My name is Mariko Okumoto. I have schizophrenia, and I work at Project Return Peer Support Network.

KC: Another question just popped into my head, but I forgot. Tell me more about being a nurse. You were a [nurse's aide], and then you got sick. What happened in that, and why did you choose not to return to nursing?

MO: Okay, because I'm a sensitive person. And I take everything the hard way, the bad way – I used to – 'cause I didn't have good self-esteem. So, whenever someone died in the hospital, I took the blame. It was in my mind – "I killed that person." So, that's what really caused me to start to drink. It got me worse.

KC: And then when you got better, you decided to work with other clients and not to go back to the nursing. Why not go back to the nursing?

MO: 'Cause I knew I would take it back again and repeat the way I felt before. But working with peers gave me the strength, and I know that if I can help other people, it would be good. Then I can give back to everybody who gave to me, who have the courage and faith to help me out.

KC: One stigma that I've bumped into in our family is that people think people with mental illnesses can't have love lives.

MO: (laughs) Yeah, that's true.

KC: How has that been true or not true for you?

MO: It has been true, but it's not true anymore.

KC: Describe why.

MO: I have a friend now. I knew him for about eight, nine years already, and we're getting closer. He has a mental illness too. His doctor told him also, "You will never find anybody you'll care about or be really good friends with." So, we're kind of both teaching the doctors something (laughs)

KC: How did you fall in love?

MO: I don't know if it's love because I've never found love before. But he cares about me, and I care about what happens to him. And whenever I'm in trouble, he comes out to help me.

KC: And he was great to drive you here today.

MO: He was.

KC: If you had to tell something to your dad to try to really convince him – and I'm sure you've tried this a bunch of times – what do you wish your dad would know?

MO: Just that I am trying, and I wasn't lazy. I realize I caused him a lot of pain, but it was not really me; it was my illness. I just want to let him know that I am doing better now. And he admits I'm doing better now.

KC: I have nothing more to ask you. You answer everything so beautifully that this just went—we've finished up faster than anybody else.

MO: (laughs) That's nice. Thank you so much.

KC: You know, you actually are reminding me of my brother 'cause he also has this very special ability that you do – just getting right to the heart of it, expressing it so clearly. Do you have suicidal feelings anymore?

MO: No more. No more. Everyday I wake up, I'm busy. I look forward to the day, and I'm calming down more. I used to be really nervous and upset about a lot of mistakes. Now I think about desserts. Every time I feel upset or mad, I say, "I'm desserts." And I think of what I can eat to reward myself for not getting mad or depressed.

KC: Well, [with] that in mind, I have some chocolate on the table.

MO: (laughing) That's great, yeah. Desserts.

**END OF INTERVIEW**