

Sanjeet Sihota talks about the importance of becoming involved in advocacy...

... Advocacy, too – being able to get into advocacy for a cause that you feel so passionate about. Like you said, coming out.. The only way, I think, to fight stigma is to come out and talk about the illness. And like—it's called "Living with Mental Illness. I think "Thriving with Mental Illness" would be better, and that's how you fight stigma, with words like that, as well. Words are so important. "Members," not – whatever you want to call it – "patients, clients." Not "schizophrenic;" not "borderline," or not "bipolar." "A person with..." at least, "a person with schizophrenia," because you're always a person first. The whole-person focus is so important; psychosocial rehab, you know. When it's a medical model, it's so filled up with illness to me. The key to recovery in the recovery model is breaking that up. Only one sliver of that should be "person with illness." You're bringing out all these life roles again – musician, friend, employee – [with] all these things, you're filling that chart up and breaking it down into all these life roles. That's recovery. By taking the focus off the illness, you're treating the illness.

READ THE FULL TRANSCRIPT BELOW.

Interviewee: SANJEET SIHOTA

Interviewer: Katie Cadigan

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I: Becoming Ill; Finding Support; Getting Back to School

KC: You're going to just talk to me. If you can, pretend John's not here. Don't look at the camera – it'll make you look shifty-eyed. I might ask you the same thing two, three times, and it's not because I want you to say a different answer or I didn't like your answer. It's probably because I heard a noise, like there's a chair right out there that keeps scraping. Sometimes there's a beep or a noise out there. You probably won't hear it 'cause you'll be in the conversation. Obviously, we're going to edit this. I'm mental health-friendly, I'm not "60 Minutes," so if you say anything you're uncomfortable with, we can take it out – which I doubt you'll do. And if you ever want to say anything over, it's fine. And then, this is going to an archive, so when we cut it up, sadly, our hour together, or whatever, will just be a couple bits, but your words and experiences live on. Okay?

SS: Sure.

KC: So, what happened in your life that led you into treatment?

SS: Well, back in 1991, when I was going to the University of California, Santa Barbara I first got ill – came on very quickly during the winter quarter, and my parents had to come up and take me out of school, like, within the first month. And between '91 and '95, I was hospitalized on three occasions, twice being at UCLA. The diagnosis I was given was schizoaffective disorder. And generally I would, during that period, I would take the medication and feel like, "Okay, I'm better now. I don't need this anymore. I hate the side effects." You know, so kind of, "Oh, I'm cured," in a sense. "And I don't want to take it anymore." And then I'd eventually wind up getting hospitalized again. So, after the third time, when kind of everything meaningful had been taken from me in my life like being a student, having friends, that I lost touch with all the friends as a result of the illness. Everything, all my meaningful activities and meaningful life roles were taken. I

call it kind of baptism by fire. And so, after that, I decided that maybe there's something to staying on the meds long-term. So after '95 was the last hospitalization. I've stayed on the meds since then and haven't had to be re-hospitalized.

At the same time, there are certain repercussions of going through episodes that are more long-term types of issues related to cognitive functioning. School, during this period of time, even when I was stable, had gotten much harder. I didn't know why. I was studying so many times harder and I was taking a lesser load, and I was still struggling. I thought, "Maybe I need to be closer to home to cope with the stress better. I'm not sure what's going on." So I came closer to home. I took a class, and I was still struggling. Of course, I did okay in the class 'cause it was one class to me, before being a full-time student and being able to handle it. I thought, okay, maybe I needed to get a psych test done. So, I came here to UCLA and did that. And what came out of that was I had pretty significant memory impairments, working memory. Specifically, working memory is kind of like a digit scram. How much can you remember in that span, like immediate recall? So, the way they kind of tested that was they'd read off a list of things, and right when they were done, they say, "What was on the list?" And I'd get the first couple and the last couple. I like to refer to it as when you're in class, you're taking notes, you're listening to what the professor just said and it writing down. At the same time, you're listening to what the professor is saying *now* so you can write it down. So, it involves doing two things at once. So, that was really impaired. At the time I tested, it was at the bottom of the one percent of the population. So, there's some retention and organization, but that was the biggest thing. What I was told by the doctors [was], "This has been seen in other people who have had psychotic types of episodes – these types of deficits. Generally, some more long-term issues are likely to remain. We recommend that Mr. Sihota stay on his medication. When he does try to reintegrate back into school, he should take no more than one class at a time and avail himself of a tutor."

So, at that point, I was kind of, what do I do now? All my career goals, all my dreams, all my everything was just shattered. For about a year, I was really down. And I just stayed home, watched TV all day. My parents were worried. [I] didn't do anything, wondering do I still want to continue? Do I still want to try if I cannot reach the potential that I could before? Is it still worth it? In my culture, Indian culture, education is so valued. My dad's a professor. My mom was an economist. My sister's an attorney. My brother-in-

law's a lawyer. So, I always wanted, okay, I'm going to finish school at this time, I'm going to go to grad school at this time. I'm going to have a wife at this time, kids at this time. And everything kind of was laid out in terms of time frame. And that was kind of a complete loss of control; that I felt like I was no longer in control of my life. And was it really kind of worth it to continue? Was it worth it to go on if I couldn't live the life that I could have before? And so, I was really down, pretty down for about that year, wondering what to do.

Then, through a friend of mine, which is really weird – he was hospitalized the same time I was at UCLA. We were acquaintances in high school, but not close friends. But we knew each other. He was star athlete, had a full scholarship to UCLA for volleyball; a student; got real good grades; was in a fraternity – all this stuff. He actually got schizoaffective disorder, and it completely changed his life. Now he's unfortunately in kind of a board and care setting. I try to keep in touch and be supportive, but it's amazing from what he was and what it's done to him. And yeah, I don't think he's gotten enough of the right support to really help him become more functional and garner more type of life roles.

Anyway, so he was actually going to an organization called The Life Adjustment Team, which is in Culver City. And there was a guy there named Jamie, who kept telling, through him [my friend], "Oh, tell Sanjeet to come check out the team. Tell him to come by, talk to me." So, he kept sending that message. And I was uncertain, I felt like nothing was going to work. I hadn't made a decision whether it was worth it to try or not. So, eventually, through kind of his persistence and sending messages, I said, "Okay, I'll go check it out." So, I checked it out, and I slowly started working with them. And what they help to do is they offer psychosocial rehabilitation, which was they would slowly help me to get back out in the community. I would actually drive over to their office because I was living in Huntington Beach at that time. So what they would do was we'd go out with one of the staff there. They'd take me out into the community, whether it was playing tennis again – simple as that – that I hadn't played for years; whether it was going out, and just being around other people, in a group who had mental illness. I was so isolated before. I thought, "I'm the only one dealing with this. I'm the only one who has to go through this." And now that I met other people that were dealing with similar things – some who were striving, still doing the best they can; some were lower-

functioning. I was like, you know what? Maybe I should try to make a life for myself, as well. So, slowly by getting out, by doing more, by garnering some more life roles, I kind of built up more of a life for myself. This was probably about over a year and a half.

But one of the keys was the relationship that I developed with Jamie. It was a relationship that I never had before in the mental health system. My experience going through a lot of this system, for years, was it was very stigmatizing. And I had doctors—it was kind of that pedestal – the doctor’s up here, you’re down here; it’s not on equal levels; it’s not very collaborative; “This is what you have to do.” It was always kind of talk about illness, illness, illness. And I kind of felt like that’s all I had to offer. And people treated you like you weren’t a really capable person. And you kind of felt like you weren’t getting the message that there was a lot of hope. And there’s always this distance, whether they call it professional distance, that always got in the way of feeling connected and feeling like the professional really cared about you. That had never been there up to this point, until I had met Jamie.

KC: And who was Jamie? Describe – “Jamie was...”

SS: Jamie was one of the staff at the Life Adjustment Team. And he was probably the most integral in terms of my recovery, and the reason was because he offered me the type of emotionally close relationship that is, in my opinion, necessary. And I think that there’s a lot of research out there now that shows it’s necessary for recovery. These illnesses can be so traumatic, and that type of connection is needed to give hope to the person just to start to try again. So, he offered me the type of relationship where it was more than just his job. He was able to convey that, transcend that – that “I care about you as a human being. I believe in you so much. I have so much faith in you. I know that you can make a quality of life for yourself. You still have enough capacity. You still have enough cognitive ability.” And I thought, my cognitive ability is so bad, there’s nothing I can do anymore. And so he kind of kept that faith and kept that hope until I could start, slowly, to see it for myself. Later I’ll talk about the Village, [a recovery-oriented, psychological and social service program in Long Beach] but that’s one thing that they mentioned, too, is a person carrying that specific vision of hope for higher quality of life *for you* until you can start to hope and believe in that [yourself]. So, he really took me under his wing and made me feel special, made me feel, like I said, that he was really in my corner, no

matter what – regardless of this being his job – that he cared for me no matter what. He was so invested in me recovering. So, that type of close relationship slowly made me start to believe in myself.

There were a couple other staff – again, him being the most important relationship – that helped me get out to do more stuff. As I got out there in the real world again and started to do more stuff—again, initially just activity; having more structure; just seeing the team; getting out and doing stuff, as simple as even going to a Laker game as a group; playing tennis again; slowly built up to volunteering.

I started volunteering at a senior health center called Opica, and that was in Santa Monica. And the people that they served were older citizens who had Alzheimer's and dementia. So, I started volunteering there, and the type of work—just giving these senior citizens attention, paying attention to them, really doing active listening, reflective listening, and helping them out in groups or in arts and craft. The feedback I was getting there was so positive from them – “Thank you so much.” The staff there would tell me, “You're really good at this. You're really talented at this. Have you ever thought about going to this field of work?”

So before that experience, when I felt I didn't have anything to offer anymore, slowly when—for example, having this experience and people mentioning things – “Wow. I guess there are some things I can still offer people. I guess there are some things that I can still do,” when I thought there was nothing that I could do anymore. And I still had qualities, I guess, that I could build on and possibility make a higher quality of life for myself. So, slowly, I started to see that there's still things I can offer. Later I realized that also one of the gifts with the illness, which I'll talk about, is how it evolved me and developed my personality and characteristics. So, slowly volunteering, and then I moved up to working part-time for a movie director. And that was a really rewarding experience, just doing personal assisting stuff, got to work on the sets, got to meet a lot of the actors and things like that. And so, built up to around—over this year and a half, I was working up to twenty hours a week, but initially just started volunteering, and then it was six hours, eight hours, ten hours.

And then, at that time, I decided to take a class again, with Jamie's belief and pushing – "You can do this." Now, school was kind of like a PTSD [Post-Traumatic Stress Disorder] experience; that's where everything started. That's where all the struggles were now, and it's like facing the forefront, the reality, to me, of the cognitive difficulties. Having to face that again, having to struggle with that. So, I was very scared [about] how I was going to do. But I did go ahead and take a class. It was at Santa Monica College. And when I integrated back into school, I used all the services of the Office of Students with Disabilities. Sometimes people don't know, and you can be provided with anonymous note-taking. That's the way they did it at Santa Monica College, where there would just be a letter sent out to the professor by email – "There's a student in your class who's registered with our office and he needs a note taker." Professor would make an announcement in class – "There's a note taker needed. If you're interested, please go over to the Office of Students with Disabilities, and you'll be provided with a stipend." And at that time, I think it was 100 dollars for a semester. And so, what the student would do was the student who was taking the notes, after the class was over, they'd just go over to the office. The office would copy the notes and put it in the student's file who needed them. So, the student could come by and pick them up whenever they needed. So, it was anonymous. So, that bridged this gap of, hey, I don't want anybody to know I had a disability, not even the note taker. I don't want to let them know in order to get the notes.

That kind of helped when I couldn't get everything down. Having that as backup really helped. If I needed extra time on tests, I was able to get that. If I went to take the test alone in a setting to better concentrate, to be less anxious, they offered me that. Sometimes I used that, sometimes I didn't, just depending. They provided a letter of accommodation with the professor. So generally, most teachers when they have that, you can negotiate a little bit of extra time, like if you need an extra week for a paper or something like that. So, I used all those services at SMC, and I built up to taking two classes at a time. And I worked a little bit at the Office of Students with Disabilities as well, kind of being a physical aid to some students. And I did a little math tutoring, also, for one of the students. I worked with people who had also developmental disabilities, just on helping them with basic things – counting money, taking the bus to get to the grocery store, making a grocery lists, picking up the items, so—

(Interruption)

KC: So we're now – you're in school, getting support, availing yourself of the services, two classes at a time.

SS: So, as I integrated back into school, taking that first class going back, that's when I stepped away from the Life Adjustment Team and Jamie because I had a lot of meaningful life goals now and a lot of activity, a lot of structure – things that gave my life purpose and meaning, so I didn't need that level of support anymore. Slowly, I tapered down over the year and half using the team. And now, I stepped out more on my own. So, I was taking two classes and was using all the services and was working some with the Office of Students with Disabilities. Not to say I [wasn't] still trying, like, ten times harder (laughing) in school and working super hard. And I could take two classes, but I felt three was too much to manage. So, after two years there of—the exact place I had left off. Now I remember.

I had completely changed my major in the field I was going into. Before getting ill, I was into business. I was going to do business. I was going to be a CPA, Certified Public Accountant. After the illness, I decided that I wanted to go into psychology. I somehow want to use what happened to me. So, I went into psychology, and after two years at Santa Monica College, I was able to transfer to UCLA. So, at UCLA, it took me three years, and I always used the Office of Student with Disabilities again, which was very supportive. They were very helpful at UCLA, very supportive. I had one of the best counselors. She was actually a psychologist, Ph.D., and she was so great, and she was so supportive, and got all the services that I needed. Sometimes they advocated on my behalf when I actually couldn't take a final. Once, I had changes in medication and I wasn't doing the greatest, and I couldn't take a final. Initially, the teacher was like, "Sorry you got to take the class again," and dah, dah, dah, dah. They advocated for me and actually got me an incomplete, so I could just take the final when I was ready. So, they were very good and very, very, very supportive.

Now, it wasn't a smooth path (he chuckles). Recovery is not a smooth path. I remember Dr. Lieberman, he signed one of the books for me – his book that I was reading. He says, "Sanjeet, often the journey of recovery is not straight up the mountain,

it's around the mountain." So, some people will call it recovery is defined by setbacks. I like to call it recovery is defined by opportunities to learn, to try something different the next time, whether it is you need more support this time, whether you need more resources, whether you need to try again to be successful. And so, I fell down, like I said, a lot of times. Now I was more able to pick myself up and dust myself off on my own. For example, sometimes I would take three classes. I would have to drop one towards the end and take two classes. One class, I remember, I had to take three times. It was the hardest class. It was how to publish your own study in a journal, and you had to do a whole workup in your study and run the experiment. So I had to take one, I remember, three times. I had drop out and take it again, take it again. So, my college loans (laughing) built up a little bit.

I said, really, never giving up was the key to recovery. Never giving up, no matter what happens. So, eventually, I was able to finish at UCLA in three years. Then I transfer—that was back in 2003. I finished my B.A. at UCLA. And then I went from UCLA to USC to do my Master's in social work. There, I choose the mental health concentration, and I also chose a sub-concentration. They called it "severe and persistent mental illness," which I hate the title because it's such a huge label and it's so all-encompassing. And persistent [connotes] we don't get better. Just 'cause there's not a cure for something doesn't mean you can't recover from it. And what I mean by recovery – say you go from just getting out of the hospital. You've lost a lot of friendships. You're taken out of all your meaningful life roles and activities. Now, let's say with the right support, a year, a couple years later, now you have a social life again; you have friends again; you have activities that you're doing again that you used to enjoy, whether that was playing tennis; whether it's being a musician again, playing the drums again; whatever it is that had—you have pleasurable activities again in your life; whether you're volunteering every week where people need you to be there; whether it's you're taking class again in school; whether it's [that] you're working part-time; whether it's, wow, you're living independently in your own apartment and taking care of all your own needs. So that's recovery. And people do recover, and people do get well. I lost my train of thought for one second.

KC: You're now getting an MSW. But I wanted to ask you just say again that you hate the term – as a whole sentence: "I hate..."

SS: I hate the label, that whole label, “severe and persistent mental illness,” ‘cause it just [connotes] people don’t get well. I actually took it up with the dean at the USC School of Social Work. I was encouraged—there were a couple different deans. I was encouraged by the Orange County Dean to ask the question of “Why you keep this label?” at a Q and A for the head dean of all the campuses in Los Angeles County. And I asked the question to her – “Why do you keep this label when it [connotes] people don’t get better?” All she said was—she kind of side-stepped the question. She said, “The reason we keep that is for funding purposes.” And then she said, “I’m no longer going to address that question.” So, she kind of side-stepped it. The other dean – he was very forward – he said, “Sanjeet has really started this off on the right track in terms of asking the tough questions.”

Going into this too, in terms—talking about stigma a little bit now in terms of professors and academics. Some teachers were very supportive. For example. the dean of the Orange Country campus was very supportive. I don’t know how I would have made it [without that dean].

II: Fighting Stigma

KC: Would you come out to all your professors?

SS: Well, yeah.

KC: Can you say, “I would..”?

SS: I would come out to all of my professors. Especially in the context of when I knew that I was going to need extra time to do something, I would come out and describe my situation, why I needed the help and—

KC: Would you say “I have a disability,” or “I have schizoaffective disorder”? How would you come out?

SS: I would say kind of that “I have a mental illness.” I would describe the situation. I’m sure that I’d mention schizoaffective disorder, and I mentioned—I would go a little bit into the cognitive stuff, why it’s difficult, and the working memory. I would describe—for example, writing a paper, I would say, “Often when you write a paper, you’re trying to keep one sentence after the other after the other to form a paragraph. And that takes working memory, keeping that all in your mind. Oftentimes it seem like when I write or try to do it, it’s like one sentence stands alone. It takes me a lot of time to put it together in a paragraph, to keep redoing it and rereading it to make sure that a sentence is following another, instead of before, keeping it all in here and writing it all down.” And so, that helped, somewhat, to understand. Now, along the same lines, some teachers were more supportive than others. Other teachers, whether they thought you’re trying to con them or whatever. I would say, “You know, I can bring in the documentation [he chuckles].” I would get the documentation from the Office of Student with Disabilities. But I said, “I also can provide you with the test if you want to see it.”

But they didn’t really have, they didn’t provide note-taking type of services in the graduate program, the MSW program. So, outside of a Letter of Accommodation there weren’t really a lot of other services that I got in the MSW program. Now, back to—some teachers were more stigmatizing than others. The biggest support that I felt was the dean of the Orange County campus. His name was Dean Carmona, to mention his name, ‘cause he was so helpful. And he would tell me, “You know, Sanjeet, since I can’t live in your shoes, I don’t know what it’s like. I don’t know what it’s like to go through what you’re going through, the struggles that you’re going through. I just want try to be supportive as possible.” He said, “I have a son who has learning disabilities, and things get difficult for him. And I can’t walk in his shoes either, and I don’t know what it’s like. It must be really difficult. It must be really hard.” He was just so supportive in terms of whether it was not letting me give up when things got hard, when teachers were hard; [supportive in terms of] believing in me so much, to such an extent, and treating me like I was very capable.

However, there were other people – I remember one teacher—I needed extra time on a paper, and I needed more than that extra week for the paper, and when I couldn’t turn it within that week, she went off on me. She was yelling at me in the office, saying, “You really got to question whether you have what it takes to be a social worker. And maybe

this isn't for you." And just yelling at me, and there were students outside. So, I wound up turning in the paper in late, like a week later than she wanted. She just ripped it up and took off all these points and gave me a D or F on it. And she reported to the dean and my field instructor that "Sanjeet's not going to pass this class. Recommend him to drop." And so, I had a meeting with the dean and the other field instructor teacher, and they advised me, "You should drop this class." Things go in segments, so in terms—I would have to drop other things, too, like my internship. I would be put back a semester in terms of taking other courses. But they were saying that you should really do this because if your GPA drops beyond a 3.0, then you get on probation, you can get dropped out of school. But I said, "If I still wound up with almost a perfect score on the final paper, I could still pass with a C, and as long as I had grades in my other courses that pulled up the average to a B, I could still move on and keep up."

So I said, "No." I had sign off on, "I'm going against advice and blah, blah, blah, blah, blah. So, I refused to sign off. And so, the final paper – I really worked hard on it. Got a lot of help in terms of tutors and stuff like that and had people proofread my paper, because I was so determined to pass the class. I went to this teacher several days before the paper was due, because she had said, "People can come by earlier. I'll take a look at the paper." So, I went and did that, but because she had already labeled me as whatever, a "student with character issues," or whatever—"Can you please look through it?" Because I worked so hard, I hadn't really slept much the night before. I hadn't shaved, so my beard was there. So, I went in, and she said, "No. I'm not going to read this paper. Look at you – you haven't shaved. You look so unkempt. You don't even look like you've showered. You can turn this paper in when it's *due*." Blah, blah, blah, blah, blah. Yelling at me again.

And I just left, and I told the dean about it. And the dean approached her and said, "You're no longer allowed to speak to this student—" the dean of the Orange County campus. And he said, "I think I may know the student you're talking to," and no longer approach that student. So, I turned in the final paper, and I got a really good grade. I got 34 out of 35, so I just passed the class. But she kind of put this last jab in there, where she said—they had this paper that they put in our files with the final grade and the tally up and the score. And she put in there a couple words saying, "Due to your psychiatric disability, I'm giving you one extra point," to rub it in. So, I showed that to the

dean and my field instructor. And they were like, “We have to make a copy of this right away,” and dah, dah, dah, dah. And they did that. Later, the dean of the Orange County campus, Dean Carmona, said that I could’ve, if I wanted to, sued the school, based on that. I could’ve taken legal action. The teacher was spoken to and all that, but I could’ve. He didn’t tell me that before, but he said, “You could’ve done that.” So, that was a very stigmatizing experience.

KC: You had the issue of stigma in terms of the label of the program you were in. In terms of content of what you were learning in class, was the information presented, in your mind, accurately when it got to illness like schizophrenia or bipolar disorder?

SS: You know, they didn’t really talk much about recovery. In terms of the symptoms and stuff, yes. I learned more about recovery and the recovery model and how that applies at my internship at the Village. Also, in the final class that I took as a part of the severe and persistent mental illness course—but even like, I remember some of the teachers – some were very accommodating, but some, also, kind of were like, “If you don’t turn in a paper at this time, we’re going to dock more and more and more and more. So, when I couldn’t, I had to take a class a couple times.

So, I think there needs to be a lot of advocacy, especially when you have this cognitive stuff and you want to finish school, if you want to do grad school. I think for these types of illness, there needs to be, in my opinion, a specialist as a part of the Office of Student with Disabilities, who can advocate on your behalf, who can really both foster the one-on-one-relationship with you and take that and explain to professors [the] difficulties – why this is difficult, so you can interact with both the assistant dean calling you into their office to, like, discipline you and say, “You have until *this* date to do it, or else...”

You really need the person ‘cause it’s stressful enough to try to do all this with school and get it all in and also deal with all this pressure – having to fall back and fall forward because people aren’t willing to give you enough accommodation. So, you really need that. And I talked to, again, Dean Carmona about that. And he said, “That’s a great idea” – having that as part of Office of Student with Disabilities; having a person who’ll come and advocate for you and explain the difficulties and the research, the neuro-psych stuff; help people to understand when they don’t. They’ll think it’s a character

issue – “You’re lazy, you’re this and that.” It’s *nothing* like that. I think people who have this want to work much harder to compensate and be successful. I guarantee you that I was working so much harder than a lot of the other students. If the teachers could see that, the degree to which I was working, they would have given me the extra time. [They would have seen] that I’m not being this lazy person, and stuff like that. So, I think that’s really needed as a part of these programs.

KC: It’s interesting – that perception of laziness is what a lot of families think when their children get sick: “It’s lazy. You’re a bum. You’re a this or that.” And it sounds like you didn’t have that in your family.

SS: [In] my family, no (he laughs). That’s not true, actually.

III: The Role of Family;

KC: Let’s switch gears and talk about what the role of your family’s been.

SS: My family – they were always kind of like, “This is for the professionals to deal with. We know you have a problem. We know you need help. So, we’ll provide all the financial means to get that help for you.” Were they able to really relate, really try to empathize, really try to be compassionate or walk in my, kind of, shoes? No. They weren’t good at doing that. And advocating, for example, for treatment, going to NAMI – National Alliance on Mental Illness – being a part of that, taking the Family to Family course. Whether it was the issue of stigma and them not wanting to do that, not wanting to think that, oh, they might meet some other family who knows them, I don’t know. They weren’t as involved in my treatment. I felt, as I started the process of recovery – going back to school and had to drop classes, taking them again, they were like, “Are you ever going to graduate? Are you ever going to finish? You’re our only worry. You’re our only concern. Is this ever going to happen?” So, yeah, I did feel stress and pressure from that.

I did have try to overly and overly explain, “*This* is why it’s so hard. It’s ‘cause of these deficits. Yes, I seem okay on the outside.” I’m the only one who recognizes that. If a person doesn’t have, for example, a working memory impairment, they don’t recognize

it. It's so second-nature to people in their lives. If you don't have that deficit, you don't know what it's like. You can come off on the outside as, "This guy can talk, this guy can dah, dah, dah, dah." Unless you have to deal with that, you really don't know the hardships of it. I had to explain to them, and keep explaining to them. My dad, he came from India – "I had ten dollars in my pocket. I worked so hard. I had no scholarships, and I worked nights as a janitor to get my B.A., my Master's, my Ph.D. Hard work pays off. Hard work accomplishes everything." Kind of the "pull yourself up from the bootstraps." Then I'd say, "Don't you understand?" They'd say, "Okay, we know you have a problem," and dah, dah, dah, dah. But I did get—at one time, I would never not want to have the parents that I had, because they were very supportive in terms of always being there financially and always saying, "Okay, we'll get you all the help that you need to deal with this, to overcome this." And at the same time, they didn't really go out and get a lot of education to understand.

KC: It sounds like it was your problem.

SS: I would kind of—yeah. I took them to conferences. (he chuckles) There was Meeting of the Minds in Orange County, which is a conference every year, and I took them. And there, people there were so surprised that I actually brought *my* parents to the conference.

It was interesting, several months back, I got an award through SHARE, which is a self-help organization that runs self help groups that are all free for people. And I got a SHARE for alternatives in terms of self-help 'cause I do NAMI education, recovery education course for consumers. So, I got this award and I had to go up and talk and stuff. It was kind of a big thing, presentation. I had people there. And it was the event that I've actually invited my family to. It was interesting. Sharon Dunnis, who's the president of NAMI West L.A., asked my mom, "Why don't you be more part of NAMI? You can take the family education course. You could help us so much. Your son is so amazing. He's so great. He does all these things for NAMI." (laughing) And my mom goes, "Well I donated my son to NAMI. I think that's enough." (he laughs) That's her response. Even after getting the award and everything like that, that my mom was more focused on, "Don't eat that. Don't eat that. You're gaining weight (he laughs) – at the dessert table," instead of, "We're so proud of you," until I asked, "Aren't you proud of

me?” Then they’re like, “Oh, we’re very proud of you,” and this and that. But they were never like that.

But considering, when I graduated at UCLA, knowing how difficult, my mom cried uncontrollably. She couldn’t stop crying. My dad was like, “We’re so proud of you. We’re so proud of you.” But along the way, unless I asked, it wasn’t verbalized. Even finishing my MSW, too, my mom was crying. My dad was [saying], “We’re proud of you.” But kind of along the way, it was like, “Are you ever going to finish?” Dah, dah, dah, dah. “You’re *not* working hard enough,” (he laughs), and stuff like that.

V: Life Today; Recovery Culture; the Gifts of the Illness

KC: Let’s fast forward to today. Can you describe your life? You’ve gotten an MSW. What is your life like today?

SS: Well today, you know—after finishing my MSW in 2007, instead of—I had offers to go work for the County in an MSW position. Instead of doing that—about six months before I graduated, a friend who had also gone to the Life Adjustment Team, who’d I met back in—I first went to the team in 1998 to about 1999, 2000. I met him there, lost touch, and then he got back in contact with me six months before I was graduating. And said, “I’m using my story to help other people to recover, to go out there using my lived experience.” He asked me if I wanted to be a part of it. And [he said], “You have, now, both lived and learned experience. Do you want to join in this endeavor of mine?” So, I said, “Okay. I’ll give it a shot.”

He knew some people that—we had speaking engagements, like at NAMI through Sharon Dunnis, at NAMI West L.A. speaker meetings. We were able to go and talk about our stories and what we offer in terms of helping – similar to what L.A Life Team does in terms of going out into the community, connecting with people, using our stories – which really helped to connect – getting them out and getting them doing more. “Hey, I can do it, you can do it too. And getting them more life roles and things like that. So, I got a lot of speaking engagements through NAMI.

I worked with the owner of the Life Adjustment Team – Pete Lynette – who kind of mentored me and guides me, both business-wise, networking, as well as making sure I'm on the right track with my clients, 'cause he's done this for over 30 years. They were one of the first organizations to go out and get people out of their settings and get them doing more. So, I've networked, I've met different doctors through this. I've gotten referred clients through some of the psychiatrists at UCLA, some through the Life Adjustment team, some through speaking engagements at NAMI. Loved ones will come up and say, "Can you help our son?" or "our loved one." That's what I do, privately.

KC: Okay. Can you say in one sentence: "I'm a private..."

SS: I'm a private mental health provider. Some people use pro-sumer. You know, (he chuckles) you're both a consumer of mental health services, as well as a provider of mental health services. I guess its unique 'cause there's not a lot of people who offer both that lived and learned experience to help other people to recover. One thing I've noticed, for example, at the Village [is] they do have more people like that. And they don't hire, now, based on your resume, or your accomplishments or your accolades. They would actually prefer people who necessarily haven't gone through professional program, because then they have to retrain them because they're looking for people who [they can ask] "Okay, what's something that happened in your life that changed your perspective or the way you view things? What's something you went through?"

The reason they do that is because generally, people who've been through something has kind of shaped their view on life and the world, and they go to that personal level to connect, to help other people to recover. And it's more from the friendship perspective and the friendship style than the professional type of style. It's kind of like, okay we have certain boundaries – you never get intimately involved with a client; you never have sex with a client; you never do anything to intentionally harm a client. But beyond that, there's a lot of things that get in the way of treatment relationships, professional relationships – the boundaries that get in the way of helping these people to recover and really being there for them. That type of, "I'm going no matter what-" type of relationship that really is what makes a difference.

One special relationship can make all the difference in the person's life for recovery. Carrying that hope; empowering the person until they can believe in what they have to offer; getting them to take more self-responsibility, more [early] on; helping them get those meaningful life roles. Once they have those things, they start to manage their life on their own. Now, do a lot of people get that support, enough support in terms of a person who can walk along side them in the community? Not [a person who does] for them, but to help them to negotiate and get the services they need; help them to overcome things that are harder to do on your own; mentor them; social coach them. Sometimes it's too hard, initially, to get back out there on your own. It's so overwhelming, it feels, and if you have somebody to walk alongside you to bridge that gap, it's a lot easier. They help you get out there and do all this, more.

But that takes more man hours. That takes seeing somebody, initially, on a daily basis, [or] at least every other day and helping them get out there and helping them do this stuff. A lot of times, that's not available, especially to families who can't afford it in the mental health system at large. I wish that there were undergrad programs who maybe had a requirement for students in a certain—if they want to work with the population, do a certain amount of volunteer hours. They could provide the man hours to these Full Service Partnerships [a program funded by the 2005 Mental Health Services Act] and stuff to see the patient every day or every other day. They could get credit as part of these programs it would be just great.

Even with the passage of Prop. 63 [the initiative that became the Mental Health Services Act], I still don't see a lot of that – the intensive services that are really needed – that culture, special culture

KC: What are the holes in the mental health system? If you have list the holes or the things that need to be fixed right now.

SS: The holes are, I'd say—

KC: "The mental health system needs..."

SS: Culture, big time. Recovery culture. What I mean by that is like the warmth when you walk into a place. Just, it's not there for a lot of places, except for the Village.

KC: Can you say, "The mental health system does not have the warmth...?"

SS: Yeah. The mental health system does not have the warm type of culture and environment when you walk into the setting where services are provided. I can contrast it with the Village. Its simple things, often, in the environment – changes that you can make. For example, not having metal detectors; not having security guards; having more of a community watch program. If something's getting heated, staff hear it and staff come to that area and that situation. Don't intervene physically, but just kind of circle it and observe it and let it deescalate. Let the person act out, let the person finish until they leave, instead of tackling them, instead of calling security, instead of all that 'cause that's just too stigmatizing. Bathrooms shared by staff and members – as simple as that. [Another change is offering] large open spaces for people to get together, not closed-off office spaces. Not having to—you have to have an appointment, you have to have dah, dah, dah, dah. The Village has a cafeteria where staff and members are eating together, eating food made by the members. Not having an appointment to eat together. Just, "Hey, what are you up to? What are you doing, man? You want to get something to eat?" Just as a conversation, to have a conversation, to hang out.

It's that type of environment. It's that type of treating the person also like they have capacity, potential. Again recovery, medical model – shifting to the recovery [model] from the medical model. It's about what you *can* do, not what you *can't* do. It's about your strengths, not your weaknesses. It's about your abilities, not your disabilities. You're going to have some symptoms, but hey, let's do what it takes to move forward with the rest of your life. Treating people as more resilient than fragile. Giving all the support out in the community, helping people to risk-take—whether that's independent living—not care-take for them. That culture. The special people that it takes to make that culture is what's missing. I don't know how to transmute that. I don't know whether—I know people at the Village are trying to get out there into the county and trying to train people and trying to teach them this. There's a Village immersion program. Can you retrain these mental health professionals that have been so

entrenched in a certain model? To come more from their warmth and recovery perspective?

I think that's the biggest struggle. And that's what's missing the most is the culture and the values that promote the capacity of the person and a place that can engender such hope, that "You are capable. You can recover."

KC: So, in the community at large—we've talked about stigma within mental health care, within university environments, [within] family. But in terms of the general public, what do you wish, or what are the one or two things you wish people understood that they don't get?

SS: Well, one – I think that—leading into an answer to that is that I don't necessarily think that education is necessarily the answer to fighting stigma. There's so many people in the mental health profession and field that can be more stigmatizing than society in general. I can tell you that from my own experience going through the system. In my opinion, it needs to be having a personal relationship with somebody who has a mental illness. That's what really can transcend the stigma that's out there.

The question was how could that happen? That's hard. I was thinking of the type of organization—let's say, like, Best Buddies. I used to be one of the directors for Best Buddies when I was at UCLA, which is an organization that pairs developmentally disabled with college volunteers and fosters that one-on-one relationship by going out once a week and doing something with them; calling once a week and just promoting one-on-one [relationships]; having big, large community events – a picnic with all these games and smaller sub-group chapter events, that you'd go out to Laker games or whatever.

And I think that having a volunteer organization like that—I've spoken at a lot of different undergraduate classes here at UCLA – just asked through NAMI, asked my professors, "Can you tell them? Let's talk about the experience, make this real-life for the students." And at the end I talk about an organization like this 'cause people often ask, "What we can do?" A lot of students come up afterwards and say, "That's such a great idea. How can I be a part of that?" Whether it's they have a loved one who has a mental illness,

whether they're just interested in the field, some even—if they've had a mental illness. So many people have come up and asked that. So, I think if an organization—could develop an organization like that and really have people foster these relationships, that through those experiences, it can spread. And the people that—they can bring a friend to meetings with them sometimes – “Hey, met my, buddy. We're going to go out and do this and...” I think that ripple effect can help fight against stigma.

KC: How about just the simple fact of coming out for people. There's so many people who don't share it.

SS: Right. That comes on to, I think, the gifts of the illness. Now going into the gifts of the illness for me – 1991 'til, I guess, 2007, after graduating and having something that sustains my livelihood and stuff. It took 16 years to eventually finish school. Yes, sometimes I wasn't in school, sometimes I was in. So, the road was long to recovery. And it was interesting – I never really celebrated my birthday until, like, 2007. When I graduated, when I was able to support myself, my parents were less worried. [I felt that], “Hey, I really accomplished something now. I could really celebrate something now.”

And I think about a year and half to two years ago, I started also to recognize the gifts. Actually two to three years ago – [recognize] the gifts of what I've been through – one being I am doing something I feel that I was exactly placed to do here on the earth. Some people say that's a spiritual experience, whether you say God has placed me here just to do this. I have such conviction in that and such faith in that, that I'm doing exactly what I'm doing here, placed on earth [to do]. I don't have to go through a mid-life crisis. I don't have to deal anything like that. That's a gift of the illness. That's a spiritual experience.

Number two is that it has evolved me into a much higher-evolved, self-aware, connected to that higher self of a person. Before the illness, I was much more selfish, much more egotistical, much more “Me-me-me,” self-centered. Now I'm much more thoughtful, much more giving, much more generous, compassionate, empathetic – not just to people who have a mental illness, but [to] any people who are suffering. So, that's kind of priceless. That's really priceless in terms of, you can't put a monetary value on something like that. I'm not sure if I answered—what was the question again?

KC: You totally answered fine. And just to add on that, on the benefits – I was asked to be in a lot of research programs about siblings, in the early years. And they would always ask about the hardest thing, the worst thing. And we'd get to the end of the interview, and I'm like, wait a minute, you didn't ask the benefits. And [in] our family – same thing – empathy, but we had a family healing.

SS: Advocacy, too – being able to get into advocacy for a cause that you feel so passionate about. Like you said, coming out.. The only way, I think, to fight stigma is to come out and talk about the illness. And like—it's called "Living with Mental Illness" [the original name of the mental health clients' section of the UCLA/DMH project]. I think "Thriving with Mental Illness" would be better, and that's how you fight stigma, with words like that, as well. Words are so important. "Members," not – whatever you want to call it – "patients, clients." Not "schizophrenic;" not "borderline," or not "bipolar." "A person with..." at least, "a person with schizophrenia," because you're always a person first. The whole-person focus is so important; psychosocial rehab, you know. When it's a medical model, it's so filled up with illness to me. The key to recovery in the recovery model is breaking that up. Only one sliver of that should be "person with illness." You're bringing out all these life roles again – musician, friend, employee – [with] all these things, you're filling that chart up and breaking it down into all these life roles. That's recovery. By taking the focus off the illness, you're treating the illness.

In terms of, again, sharing your story, what I like to do is I don't say it initially. Let's say it's work, or a work setting. Now I do because of the field I'm in and what I do. But in a work setting, I wouldn't initially share because I wouldn't want people to look through the prism [of], "Okay, this guy is having trouble doing this or that because of mental illness." When they saw I could do something, when they saw I was capable of doing something, then I come out, and [they would] say, "Oh, this person [has a mental illness.] I would have never guessed. You're doing so well," this and that. "I wouldn't guess you have schizoaffective disorder or a mental illness."

So, that's how coming out and sharing in terms off—I've talked at, through NAMI, a couple junior highs. We're going to go talk at Crossroads, Crossroads School on March 10 to share our stories to help to fight against stigma. So, I think coming out and

speaking at engagements and showing people your capacity, your capability, your story, what you do now, I think, breaks down what, traditionally, people think of people with mental illness – as not being capable of much, as only being able to be care taken [of].

I think that a lot of the system, when it care-takes for people, they are not allowed to move forward and recover. For example, I think board and cares, if they should be used at all, should only be use as a stepping stone to independent living. You keep somebody in a board and care – food's prepared, they're given their meds, all that stuff. You don't get to learn any more independent living skills. You don't get to learn all the life skills to have your own apartment. You don't get the experience of writing bills, writing a check, managing that. You don't get the ability to learn how to cook and make meals for yourself. You don't have all these things that you can be learning that promote your recovery even further and develop more of your potential and capacity or person. It stunts your development to your true potential.

KC: We're going to stop. Is there any big topic I've missed that you would want people to know—

SS: After I leave here (he laughs), I'm sure I'll pick them up.

KC: The main this is any—the whole point of this is anti-stigma piece. So, we're trying to get at what are the biggest misperceptions? You've hit on all the hot buttons and spoken really beautifully from your experience. So, I'm not feeling you for more—

SS: Well, the great thing that I usually like to say is, diagnosis is not a destiny.

KC: On that note, I want you to say your name and your diagnosis.

SS: Sanjeet Sihota—

KC: "I am..."

SS: Oh, I am Sanjeet Sihota, and my diagnosis was schizoaffective disorder.

KC: We're now going to be quiet for minute so John can record the sound of the room.
Again, say it—

SS: My name is Sanjeet, and I have recovered from a diagnosis of schizoaffective disorder.

KC: Quiet, close our eyes, be grateful for our time.

END OF INTERVIEW