

Dialogue Summary

Allegheny County Coalition for Recovery Psychiatric Residents' and People in Recovery November 2, 2011

Sponsor: The Center for Public Service Psychiatry of Western Psychiatric Institute and Clinic, University of Pittsburgh School of Medicine

Dialogue Location: Sterling Plaza, Oakland, Pennsylvania

Facilitators: Wes Sowers, M.D., and Charlene Saner, C.P.S.

Participants: Fifteen individuals participated in the dialogue. Two were facilitators, six people who identified as being in recovery with mental illness and/or addiction and six psychiatry residents, and two medical students. There were two observers.

Summary writer: Meg Park

Welcome and introduction: Dr. Sowers opened the dialogue with an overview of the history, nature, and structure of facilitated dialogues and opened by asking those present to introduce themselves and state what they would like to gain from tonight's dialogue. Out of these introductions came some general themes.

General Themes: Reciprocal stigma and assumptions, the role of Certified Peer Specialists and 'coming out' as a professional, hiding from each other, defining the roles we assume, the role of psychotropic medications and side-effects.

The following is how people responded. Those who have received psychiatric services are indicated as service recipients or "SR" and the psychiatry residents and medical students are indicated psychiatry resident or "PR". The dialogue proceeds as it developed in the room.

PR: People have told me of their fear of having a diagnosis put on their insurance claim and then being labeled.

SR: People don't like me when I tell them why I'm on SSDI. I have paranoid schizophrenia.

SR: It hurts me in my soul to see us Certified Peer Specialists (CPS) to have to deal with clinicians that treat us as "less than" and separate from them. They seem to say, "Stay in your role or else." They have low expectations of us as being non-professional.

SR: In order to get certification a person needs to go through full two-weeks training. I understand what he's saying. I feel "less than". Even saying I'm a CPS—I'm outing myself.

SR: There are levels of hierarchy with educations and degrees.

SR: You lose your influence when you get a diagnosis—with your family or on the job.

SR: I am new at being a CPS—I don't feel the stigma. I think it's from the hierarchy—if they don't stigmatize you the rest won't. Labor gets jealous of you.

SR: I see the stigma less now that the recovery model is gaining ground. I have been a CPS for four years now and I have seen the difference as the recovery model gains on the medical model.

PR: It may seem the higher up with degrees you have more influence and power but the peers really do. You are the beacons of hope.

SR: [Question to providers] Would you date someone with a mental illness? I provide services too and I know clinicians say one thing in front of clients and another behind closed doors.

PR: There is the assumption that docs don't have mental illnesses. That is wrong.

- **Facilitator: What I am hearing is a lot of assumptions.**

SR: I didn't assume.

PR: Providers don't tell if they have a diagnosis. We are taught to be patient-centered.

SR: The first thing I did when I walked into this room was to look around to see who were consumers and who were psychiatrists. I can tell who is who.

- **Facilitator: Why is that meaningful and why is it important?**

SR: Because after 7 years I have received so much prejudice at work – I am very angry. People who have mental illnesses are very, very intelligent. They will hide their true selves from you.

PR: How come?

SR: Hurt and pain. Sometimes the doctors don't act like human beings. They medicated me according to the severity of my relatives' illnesses, not my more moderate version of the same illness.

- **Facilitator: What about hiding? Anyone else?**

SR: I hid. My first experience was terrible. My family was against it. My first psychiatrist was distant. I left and didn't return for years. The second one I got was worse with medications. I felt like a guinea pig. He upped the dose after I told him I was like a zombie. So I quit and went off drugs. The third one was at Mayview State hospital. He yelled at me! He wasn't good and he forced drugs on me that did help me.

PR: Tell me about the forced medication.

SR: I felt like I was raped. I got held down, my pants were pulled down—I was very angry. The fourth doctor changed the drugs that had worked well. There was no real relationship there. The fifth one I like. He takes time with me. He used vitamin E to fight and eliminate side-effects (facial tics). I like being stable with him.

- **Facilitator: Do you still need to hide?**

SR: No.

PR: When did you stop hiding?

SR: When the doctor who gave me the medication that worked came out of hiding.

SR: When I first went in I didn't even tell my family.

SR: My doctor didn't listen to my complaints [about weight gain]; after months of seeing him, one day he said, "Oh! You're heavier!" Things got worse with him, not better. I have a different one now.

SR: Same with me. I talked about not being able to keep my legs still. No one told me this side-effect could become permanent!

Why don't they tell you about the side-effects? I want to know – the positive and the negative. Then I had a T.I.A. My words wouldn't come out right. I felt so hurt. He didn't even apologize for how much I suffered with the side-effects.

SR: I was an LPN. I never hid from anyone. I had great care. My doctor took me off slowly. He told me I could work. I was 'okay' he said. I got hope and encouragement from him. But he didn't listen and I had a relapse. I was stressed and he pushed me out the door.

PR: Everything is flipped too. Sometimes the illness gives you a bad face. They already don't like you and then the drugs you give them have bad effects. As a doctor you are set up to be the enemy.

SR: I hide because I want you to come into my world. Counseling seems more humane. Who are you that I should let you in?

PR: Because you're vulnerable?

SR: We need to know you actually care.

PR: That's universal—feeling safe, being present with compassion. We are taught to be medical doctors not counselors.

- **Facilitator: How does it feel, for the psychiatrists, to have the stigma on you?**

SR: I thought if I told the doctors everything they could cure me scientifically.

SR: I always poured it all out. But it was just, "take your meds, take your meds." He called me a "typical, textbook case." I spent 15 years suicidal. I got the most help finally from a CTT team.

PR: I have heard this a lot. My colleagues doing that. How much do we do it and don't know it? I have the luxury right now of spending more time with people. I fear I won't always have that.

SR: You didn't answer the question! How do you *feel* about the stigma on you?

PR: I didn't think. I'm sorry you have that experience

PR: I feel bad. It's frustrating and disheartening that what I've chosen and now doing means that I am the enemy.

PR: There is stigma within the medical community too for psychiatrists. Patients treat me differently due to my being a primary care physician as well as a psychiatrist. We do carry the weight of some horrible things that psychiatry has done through the years.

SR: Let's go back to my issue on internalized stigma. I love my job, but I hate myself.

SR: It is frustrating to deal with the limits of illness and the lack of choices. Taking meds are nice but you still have to do it [recovery] yourself. So you blame yourself for not getting better.

PR: When I listen I hear grief. There is disparity between what we hoped life would be and what we have to accept with an illness.

SR: When you see clients, do you think about trauma? If so, can you treat trauma and not go with medications?

PR: 80% of people with mental illnesses have a trauma history.

- **Facilitator: We have talked about barriers. Let's talk about how to get around them.**

SR: I have a hard time with telling people I'm an CPS. I am in a Master's program. I went the university disability services office but then I told them I was a diabetic—not that I had a mental illness. I was bothered by the fact I couldn't say that.

PR: I like the people. I like to help people with side-effects. I try to say what I'm thinking out loud.

PR: What about this word "consumer"?

PR: I feel the stigma on my end too. I tell people like at a party that I am a psychiatrist and they jump to 1) "Oh you're a mind reader!" or 2) "Oh, you're crazy too!"

- **Facilitator: How do we break down barriers?**

PR: To know that people can recover. People don't know that. The general public doesn't know that.

PR: Sometime you have to set aside the mental illness diagnosis in order to get good medical care. I had a patient that had a broken shoulder and needed an x-ray but had trouble getting that because of her diagnosis. For some doctors the mental illness is all they can see.

SR: Even my family didn't understand what the mental illness was.

PR: I always use person first language.

- **Facilitator: In what other ways does language affect the barriers to care?**

PR: How you think and thus how you act. I use names, not "patient." I *feel* more personal. It makes it more personal.

- **Facilitator: How do doctors address patients and how do patients address doctors?**

SR: First names are best. I am impressed when people remember my name. It makes me feel important.

- **Facilitator: How about calling a doctor by their first name?**

SR: I have never even thought of it. I don't know my doctors first name.

SR: I don't use any name. We don't have to...I like to be called "Mr. [X]." But I don't call them anything. I earned the right to be called "Mr." coming up from the streets. I deserve the respect.

PR: I don't care.

PR: I want to be called Dr. They can us Dr. [M] if they don't want to use my whole last name. I prefer it as a woman. It is a professional relationship. I will call you what you want or "Miss" and then your first name.

PR: Doctor. It's a good reminder of my role and responsibility. It is less casual and helps me do the job.

PR: I ask people what they want to be called.

PR: In therapy it's my first name. In clinical medical office its, "I'm 'so and so', the doctor.

PR: You must fix the problem. The medical model reduces stigma. I struggle with the tension. I love the therapy – psychotherapy. It's a pleasure to be with them.

SR: How do you define the difference between the recovery and the medical models?

PR: I don't see how the two are mutually exclusive.

PR: The recovery model is being used in diabetes treatment now.

PR: The health outcome disparities make it important. How to find a medical doctor is important. I am comfortable with the integration of physical health and mental health as one doctor.

SR: No. A PCP started me on Paxil. I thought he didn't know what he was doing. He should have sent me to a psychiatrist.

- **Facilitator: One model is more prescriptive. What kind of role should a person have in their treatment?**

SR: We should be partners on the same team, united toward a purpose. Respect and knowledge should go both ways.

PR: I ask them how the medications are helping. If something is bothering you—I ask if they want a med change.

PR: I think of myself as an expert consultant.

- **Facilitator: How can we work to build that collaboration?**

PR: What happens if I don't have the time to be the doctor I want to be in a 15 minute med check?

SR: Robert Whitaker showed in Italy [sic] that you shouldn't be so quick to give meds, instead surround people with friends and family.

SR: That's not true for SPMI people. It's my experience that my life fell apart without meds.

PR: Culture is important. Some people think of psychiatrists as evil.

PR: Breaking stigma and good therapy means building a good relationship. Good doctors are people pleasers. It is all about the relationship. How much do you share? I disclose when I feel it would be beneficial and that has opened the relationship. You meet them where their at. Finding common ground. We all want to be loved and accepted. We have good days and bad. Once connections are made forgiveness can be a part.

SR: I need to take my meds to be where I am right now. Education is what is important. People don't know what its like from the top on down.

SR: How many people have had a relationship with a person with a mental illness? How do you deal with that? It is hard to be in a relationship with a person with a serious mental illness.

SR: I have a brother whose mental illness is much worse than mine. People with mental illness are in *pain*. He can't help himself. I can't help him. I've learned to capture those moments of clarity to know who he really is.

PR: I had a patient in the hospital who thought pens were guns. There was so much terror for her. You try to separate yourself so that you can have mental health yourself. I "got it" with her. She would hide behind her bed, screaming for her husband to come rescue

her. I went home and cried and cried all evening.

PR: How would you accept tears from your psychiatrists? I never share but I cry easily.

SR: I think it's wonderful to know your doctor prays. It helps to know they don't think your religious thoughts are part of a sickness. It helps to be surrounded by faith and not just science.

PR: What if your patient asks about your religion?

PR: I'd want to know why they ask. Whether I answer depends on why they want to know. Will they be disparaging? Will it be helpful to them?

PR: I wouldn't hesitate to answer.

SR: What about boundaries?

PR: People who feed their spirits tend to do better.

- **Facilitator: That's all the time we have this evening. We want to thank everyone for coming and for contributing to an excellent dialogue.**