CRD December 7, 2017 Dialogue Summary

Allegheny County Coalition for Recovery

Collaborative for Recovery Dialogues

Location: Webster Hall Center for Public Psychiatry

In Attendance: 8 Service Recipients (SR) and 6 Service Providers (SP). Charlene Saner and Wesley Sowers facilitated.

Welcome and Overview of the Dialogue Objectives and Process

History of the dialogue in Pittsburgh

Basic guidelines for dialogue participation and logistics

Introductions- Participants were asked to identify themselves and discuss what they would like to get from the dialogue.

Facilitator: **What would you like from your relationship with your doctor/client?**

SR- We don't see them often, talked 10 minutes with my doc and received a diagnosis of bi-polar should have been more time. Another doctor did come along later and say the same thing but it does not seem like enough time or enough care.

SR- Ideally for me the relationship would be like having a friend with tough love who could give both direction and perspective.

SR- There is a difference between inpatient and outpatient approaches to services. In inpatient, it is more of a dictatorship where outpatient is less authoritative.

SR- In my best experiences the doctors have felt like partners but there have been times when doctors would not listen and I have had to make changes.

SR- Every doc had a different diagnosis and over time some medications worked and some did not. I was always sure to follow their directives, but I eventually have been symptom free for 16 years. This has come to make me wonder and I would like to ask the group, should treatment be optional, do you have to see a doc?

SP- Diagnosis is all arbitrary and for billing purposes. From a birds-eye view, it can look like docs are just following a string/trail of meds. They often can treat you differently because of your diagnosis so at times we are falling short. Patients are often lucky to get 10 minutes, again for billing reasons.

SP- To address the question of do you need a doctor, I'd say Primary Care Physicians (PCP) are a great way to follow up for someone who is doing well.

SP- Especially if the doctor has known the patient for a long time.

SR- When I see my doc it's a friendly quick visit. It helps when the doc listens. Sometimes docs fail to ask why? They don't inquire about what new things might be happening and how that might relate to what is occurring. They must ask what you have done differently.

SR- There are times when I need someone to tell me what to do, a Doc has no time to be friends. You can tell if they have been listening, they will pick up on certain things. Also, I would not want a relationship with a doc where they might over step lines like making phone calls to my home.

SR- I would want them to talk to me as a person, my doc knows me well and we have respect.

SR- I have been hurt when a relationship has been too close and there has not been enough space to allow me to express my feelings freely. I would describe my relationship with my current doc as a trusting relationship. I can speak freely. I do have his cell phone number but I would never abuse it. There is space.

SR- With inpatient services you need the level of trust to build immediately. Outpatient more time.

SP- It is a struggle at times there are people who you would like to be friends with, we are taught differently at school. For example, I once had a patient who lost a cat. I wanted to say that I too had lost a cat.

SP- Calling myself "Doc' At times feels uncomfortable, I struggle with the power distribution. With PCP's individuals can talk about interpersonal stuff that we can't.

SR- If it has a purpose go for it, if you are doing it for yourself, no.

SR- I have always assumed they (Doctors) know more than me, so I listen. They are not here to talk about how they feel.

SP- The doctor patient relationship is different it is about the patient. Doctors can't steal the focus they need to hear what you are saying. We don't want to be condescending want to. We want to be respected but I am not sure if we are always successful.

SR- A few years ago, I was working with both a doctor and a student. The doctor had prescribed a medication that I was uncomfortable with. I discover that I had a better rapport with the student and as a result we could discuss alternatives to the medication and I developed a trust which allowed me to progress. I think docs at times give meds without knowing our situations.

SR- My relationships with doctors and therapists got me to where I am today. A new therapist in 2010 was the key through spirituality and coping skills, stress reduction, meditation and alternative treatments which were looked at by the new team. For me the turning point was the development of coping skill plus a great relationship with my treatment team.

SR- The relationship can be like working with a probation officer. Working with someone who you are not willing to give up a lot of information to out of fear.

Facilitator: How can the relationship help or hurt an individual's recovery?

SR- The key is control itself. It is hard to manage in a one-day setting. Staying with the same team helps. It is difficult to read scared patients especially if it is in their first crisis.

SR- Relationships can be different when the patient is older as well.

SP- Sometimes it's the luck of the draw. Both sides are hoping and treatment teams can both come and go. Often the work is damage control of maintaining good outcomes.

SP- What we can do together is make a collaborative effort to work on the same page to reach goals. We have a limited time and we need to make the most of it.

SP- Some people are just unapproachable. My first break came in the army and it took a while before anyone could work with me.

SP- Treatment is still a place for respect. Sit with patients and avoid things like strip searches. Respectful not traumatizing.

SP-Relationships are incumbent on priorities. Simple things like eye contact. On the unit we see them at their worse time we can ignore that or risk-taking things out of context. Younger doctors are trying to work more collaboratively.

SP- I like inpatient work as well. I have experience in an outpatient youth clinic, yearlong relationships. This can be tough on doctors as well.

SR, I had a doctor who wanted to prescribe a medication and he ignored what I had to say about it and the fact that I had presented him a list of medications I preferred. Sometimes doctors don't trust your judgement.

SR- Yes at times, but they should meet you where you are being willing to bring new energy day to day.

SR- The last time I was hospitalized it was frustrating, long hours. What can be done? I think inpatient has its limitations too.

SP- The DEC is influx now we are finding ways to become more recovery focused. We spend time talking to or patients about it and we hear their stories we are working to implement a triage process.

Facilitator-The issue of power, who has it who should have it and how is it manifested what are your comments related to this?

SP- Docs historically have had the power but with a recovery focus comes sharing.

SR- Relationships are more than one person, the consumer has the responsibility to express themselves.

SR- It's very important when a person wants your help, help them. But when someone comes in doing all the right things does it always work? Some cooperate but I fought. When I came to understand then I made progress. A Person must partner and cooperate.

SP- If a provider lets me know "I believe in you", I can respect his no.

SR- It helps to know what the diagnosis means especially if it is the first episode. In my case I did not know.

SR- It takes time but it saves time.

SR sometimes you can get too much info. I try not to know too much stuff I assume my doc knows.

SP- We (Doc's) don't know everything, very little at times.

SP- Sometimes you must say, this may work and let's see the best fit. No certainty.

SP- People at times think doctors get upset but when consumers have knowledge discussion can help.

SR- Best when Docs say I'll look in to it.

SR- I don't know is good.

SR- The problem starts early on as we never get information on feelings or behavior in school.

SP- Our school district is one that provides discussion on the topic so it is changing.

SR- I work in the Stand Together program which is in 17 schools.

SR- Changes will come through the younger generation. Often no one knows about symptoms. Knowledge is the key.

SR-There is an inner stigma. No one knew about mental health even in D/A rehab people don't know about mental health.

SP- The right vocabulary is important, knowing the words to us is good. Docs are trying to use more assessable language to relate.

SR- I could read and research which helped everyone to make informed decisions. My doctors did not teach.

SP the doctor can oversee the process initially and once an individual is stable you add more. You can also encourage individuals to stuff outside the treatment facility which promotes recovery

SP- When you get to a point when the relationship is equal, you don't need them anymore.

SR- Docs set the foundation they should also ask if you would like to get involved in outside activities

Wes- How do you manage disagreement?

SR-I asked for time to research so that I could come back and have an informed conversation.

SR, we can assume you were in a rational mind set.

SR-Yes when I was not rational I wasn't able to make that request.

SP- It is not often that you cannot present options.

SR- We were never given a choice back in the day.

SP- We hope this has changed.

SP- Docs must be aware of their own biases especially when prescribing meds.

SP- There is lots of emotional reactions to procedures like say ECT, you would hate for someone to have it against their will. It is not for everyone but it can be a miracle for some.

SR- Like with all medications can work or not work. Regarding collaboration the power in the beginning lies with doctors once it starts power is shared.

SP- What If someone asks for something that is not safe?

SP- Docs must be sure they are being clear and explaining options.

SR- With me there were times when I was give stuff that was new because other products were not working hit or miss everyone is different and all problems may not be resolved.

SR-Some people don't want a choice.

SP- It comes back to knowledge we have an obligation to explain.

SP- Sometimes you must stop and listen.

SR- Burden of time is on the doctor but a patient should not feel that they are neglected. That is on the doc to be there as long are they are needed.

SR- Everyone is an individual. Threat the person not the symptoms and engagement is the key. Engage the person not the role.

Facilitator-Which terms promote or get in the way of the relationship?

SP- At times I am uncomfortable calling myself doc.

SR-I am comfortable with it.

SP- At times no one believes I am a doctor, so I have had become comfortable introducing myself as such.

SR- Title not important treatment is what counts.

SR- I like to be able to use first names.

SR- The title doctor is a sign of respect.

SR- Consumer is not good.

SR- They change the names for use so often best to just use first names.

SP- Sometimes we end up relabeling people we need to change our thinking and end labeling.

The dialogue closed congenially with everyone thanking each other for a great night and an opportunity to learn from each other.