

Dialogue Summary Form

Allegheny County Coalition for Recovery

Consumer-Provider Collaborative:

Dialogue Location: Omni William Penn Hotel

Title: The Road Home; Integration of Physical/Behavioral Health

Date: 6/21/10, Morning Dialogue

Facilitators: Ken Thompson, MD, Sarah Goldstein

Number of consumer's -13

Number of provider's - 6

Session One title: Integration between physical and behavioral health services

Beginning Open- What have been some of your experiences

Consumers – C: Had trouble getting psych meds during medical inpt stay

C: PCP changed mind for writing RX for meds. Decided that psychiatrist should be writing script left C to withdraw from RX.

C: PCP said to have tests (blood work) for meds. Very positive experience

C: PCP & Psychiatrist kept in touch while consumer was in crisis. Consumer had very positive outcomes.

C: MD never goes over Meds with her.

C: Does not understand why she is taking psych meds when her problem is physical.

C: Integration takes all organizations to work on it.

C: MD in Virginia made me feel like I was the illness.

C: PCP did not address her alcohol and post partum depression; when they did she got back to work.

C: There is a difference between medical care. Docs stigmatize you by the insurance you have.

Providers – P: Lack of integration in the system and billable hours.

P: Insurance does not know who to pay for the consultation MH or BH.

P: Helpful to hear C perspective. A lot of P discomfort is from the doc's lack of knowledge. We have trouble getting information from other docs.

P: Hard for a person in crisis to navigate the system.

P: I worked at Gateway for years and never had an MD call back. Psych docs call back.

P: the discomfort of the PCP comes from not knowing the psych RX side effects and being comfortable with knowing about them.

P: There is a barrier in knowing how to license professionals.

P: Children's Hospital is working to integrate BH & MH healthcare throughout its system of care and thinks stigma is lower.

P: The momentum is good with the new administration, but it takes time.

P: Can't keep psychiatrists here especially minority docs.

Allegheny County Coalition for Recovery

Consumer-Provider Collaborative:

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

Dialogue Location: Omni William Penn Hotel, Pittsburgh, Pennsylvania

Title: Primary Care Providers talk with Behavioral Health Consumers.

Date: June 21, 2010

Facilitators: Marci Sturgeon Rusiewicz, MS, NCC, SPRP and Margaret J. Park, M. Div

Participants: Twenty-two individuals participated in the dialogue about equally distributed among stakeholder groups. Many

Represented were the following:

Self- Identified Provider: a wellness director, OMHSAS staff, science faculty at UPMC in CMHC, CNP, two staff members from family health centers, a project director of a community health center, Milestone Centers staff, therapist, , Beaver County MH RN, a physiatrist, a physical rehabilitation specialist, a day treatment therapist, a person connected with the mental health court, an inpatient psychiatrist, RN in a community center, Disability Rights attorney, an RN from Pittsburgh Organization of Women in Early Recovery, an RN/Care Manager with UPMC care plan, an MD who specializes with a program for people diagnosed with HIV, Allegheny Health Choices, VA Department of Veterans' Affairs.

Self-identified Consumers/Survivors and Family Members: Peer Support and Advocacy Network executive, Consumer Action and Response Team interviewer (CFST), several people identified themselves as consumers primarily and others as consumers as well as family members, a peer mentor and a peer counselor, Mental Health America Allegheny County advocate, National Alliance on Mental Illness,

The theme of the dialogue was the existence of the high incidence of chronic health conditions for people who have a serious mental illness and the accompanying early mortality rates of 25 to 32 years premature death from preventable conditions.

Consumers – some comments:

- **I have a fear of dying soon, any day now!**
- **All the funding goes to PH and BH gets the short end,**
- **I am constantly budgeting for all to be sure I have money for insulin,**
- **I've had to go cold turkey off meds because I could afford the co-pays. The**

- repeated withdrawal symptoms are horrible.
- You can write the drug company for free samples--sometimes you have to be proactive and advocate for yourself--you have to take responsibility for yourself,
 - I went two weeks with out some of my meds, sometimes it is my heart pill, sometimes its my diabetes pills, and sometimes its my asthma medication,
 - My sugar levels went down when I got off all my anti-psychotic drugs--i tried to tell my PCP about it but he wouldn't listen
 - One person spoke at length about her depression and the diagnosis of a brain tumor and epilepsy. She was on 7 drugs for psychosis which were not working so they would add another one,--up to 7. "No one ever gave me a brain scan, when I went in for ECT they did brain scan and found a brain tumor". Then I was going to start my life all over again and I got the diagnosis of epilepsy.
 - When I had physical symptoms of the brain tumor and epilepsy my PCP would tell me it was my mental illness or they'd just tell me to lose weight, we all don't imagine things, personal medicine helps and all the other things you can do walking, talking to a friends, all promote wellness.
 - Providers need to join CSP and ACCR to listen to us,
 - More providers should help us get to Harrisburg to lobby,
 - The poverty simulation program at Pitt is a very impactful experience to help people understand what it means to live in poverty and have to deal with the whole system (Welfare, food stamps, transportation, ...) there is much stigma that goes with poverty that gets dispelled with this program,

Providers –

- funding cuts/grants running out,
- how to communicate,
- spending time is not as big of a problems as how people get rx filled,
- operating on a shoestring it is
- It is difficult to see patients not be able to afford prescriptions,
- what is considered an essential service and what is left to provider is heartbreaking,
- hate to close beds due to not being able to afford,
- having a ph condition not recognized by BH system...usually we do a basic diagnostic check with different, if it is not discovered with the first MD the person gets a label and the diagnosis does not change.
- why don't MDs stop doing what is not working and move to what may actually work?
- Its in their heads (MDs), setting goals and not just telling people to lose weight, what can we do to help people get motivated?
- We work together to pass the information on.
- we have health coaches, even one phone call a week helps people on their stop

- smoking goals,
- we all need to lobby our legislators,
 - Warm and Friendly program at PSAN linked to the warm line, make appt to call them and/or their emergency contact,
 - poverty is really an issue in taking care of yourself,

Family member's

- Not all consumers have insight
- I love to hear the compassionate side of providers because that doesn't always come through when you run out of visits,
- A mother worried that not only was she going to die within 10 years but her children and grandchildren were also on psychotropic medication. She wondered if life expectancy was 25 years less for her how much loss of life expectancy would it be for her children...or her grandchildren.

Themes:

Participants were from a broad spectrum of stakeholder groups. Many identified themselves as either those with a mental health diagnosis who were working in the field or as family members with a diagnosis. Many of them were also in the field. The majority of participants were involved with advocacy work for one population or another.

The theme that came from many people in recovery was an expressed fear of dying—any day now. The 25 year early mortality rate was not seen as an abstract number. People in their 40s and 50s expressed fear for themselves. Those with child expressed apprehension for the consequences for putting them on medication for many years and shortening their lives. There was a sense of helplessness in the room from those who had been on medications for 20 years or more. There was also rage expressed at medical professionals who had not told family members or consumers of the dangers of the drugs they were told they have to be on the rest of their lives.

Many people across stakeholder groups, spoke of money being a problem, whether it was a person not being able to afford their own co-pays or administrators feeling hopeless and helpless that they were constantly being asked to do more with less.