CONSUMER – FAMILY – PROVIDER "TRI-ALOGUE"

8/28/04

Twenty-eight individuals participated in Allegheny County's first "tri-alogue" held at East Liberty Presbyterian Church in East Liberty. The theme for the day was: Partnerships for Recovery. After introductions and a brief history of Stakeholder Dialogues, the large group was divided in two so that everyone would have an opportunity to speak. The first hour's discussion topic was: Communication barriers between consumers, providers and families. The second hour of group discussion focused on: Personal definitions of recovery. The final discussion after lunch with everyone focused on Partnerships needed to enhance recovery.

Group A (Sarah & Paul facilitators) identified three types of communication barriers:

1. Communication barriers in the context of family relationships
2. Barriers created by the system
3. Consumer experiences with their providers

Comments relating to family relationships included:

Grudges – no forgiveness; a wall between family members; mom pressures me; living too close; no family support; rejects family involvement; family not involved during hospitalization; family not helped to adjust during hospitalizations

Communication barriers created by the system included:

Regulations that prevent communication; confusion about regulations; compartmentalized service; poor information; poor salaries result in turnover and inexperienced staff; no linking from hospital community.

Communication barriers experienced by consumers with providers included:

Some providers don't care, some don't have people skills; some providers don't know enough; African-Americans feel discrimination as a minority group; providers lack education about minority (African-American) culture; providers have different assumption (than consumers) about helping relationships; staff doesn't manage group conflicts well in programs.

Group B (Wes & Sharon facilitators)
<u>The diagnostic process</u> was viewed as a communication barrier among many in this group. There were many comments about the rationale for diagnosing mental illnesses, and how it can create communication barriers with consumers and family members.

- Consumers, many times, feel shame when given a diagnosis – a "label"
- Families can feel a sense of loss – and feel blame when a diagnosis is made
- Providers, many times, view diagnosis as a way to define and organize an approach to treatment. It also is needed to receive payment for services.

- Families related that psychiatric diagnosis dies not deal with family problems – it can even hide them. Diagnoses can hide ignorance – that is, a lot is unknown even when a diagnosis is given.
- Consumers sometimes feel that they cannot be honest with a professional who "diagnoses them" – "If I told you how I felt you might 302 me. Also, you can get as many diagnoses as the number of doctors you see.

In summary the communication barriers experienced by participants included:

1. The diagnostic process – it is experienced very differently depending on whether one is a consumer, provider or family member
2. Family relationships are greatly affected during and after a hospitalization for a psychiatric condition
3. Many times provider staff "do not know enough" or do not have an awareness of consumer needs.

The diagnostic process and its effects on communication between consumers, providers and family members was the dominant theme for one of the two sub-group discussions. The rational requirement for a diagnosis to initiate treatment was countered by consumers' experience of being labeled, and the families' frustration that a diagnosis doesn't help them to deal with the major disruptions they experience in their relationships.

The disruptions of family relationships and the pain experienced by everyone in the family was another dominant theme discussed by both sub-groups. The diagnosed consumer and affected family have different viewpoints of the problems related to "mental illness". A hospitalization for mental illness can create "a wall between family members". Grudges between family members can result. Families can be "too close" or totally rejecting. Family members are not assisted in dealing with their feelings, much less given any guidance when their family member is hospitalized. Families as a unit can feel a sense of loss, as well as rejection by others when a family member is hospitalized with a psychiatric condition.

Providers sometimes lack knowledge or sensitivity to the needs of persons diagnosed with serious mental illnesses. Sometimes providers have different assumptions than consumers about what is helpful. This can occur when a provider has not learned what is important or meaningful to particular consumers. This occurs, at times, when a white therapist works with a black consumer, and does not understand that person's cultural perspective, and does not attempt to learn about African-American culture.

Recovery Descriptions

Another important area of discussion was participants relating personal instances of recovery. These concrete descriptions of the recovery process fell into two general areas:

1. The recovering person enhancing or expanding their interpersonal relationships
2. The recovering person enhancing or improving their self-image or sense of wellbeing.

Two thirds of comments related to consumers and families seeking to improve their relationships – with each other, and consumers efforts to connect with persons and meaningful roles in the community.

- Consumers want to re-build family relationships and let family members become part of their support system.
- Consumers also want to develop peer supports and feel valued in these relationships.
- Consumers also want to contribute to their communities, to give back in any way that they can by volunteering or working.
- Families want to be OK with their situations, to communicate their needs to each other and to move on with life.

The remaining one third of the comments related to recovery as enhancing a sense of personal well being and self-image. About half of consumers' descriptions in this area related to a feeling of inner power. Specifically they said,

- A desire to make things different
- Hopefulness
- Trusting my own judgment

This increasing sense of well-being and self-regard motivates consumers to take the necessary steps to recover.

The other category of comments related to behaviors required to recover or to, "get a life". Consumers said that, "steps" were necessary in the recovery process. The recovering person needs to:

- Control behaviors
- Make positive decisions about care
- Utilize talents
- Learn to accept responsibility and be self-reliant
- Live the life you want to live

Building Partnerships for Recovery

Almost all of the comments in this final wrap-up session related to how consumers are part of families, and how important it should be to find ways to include the family or significant others in the various phases of recovery, from initial treatment in the hospital to reconciliation between family members who were alienated because of the illness.

Currently, the obstacles to family involvement appear to be artifacts of a patient focused system that indirectly discourages family involvement. The behavioral health system should look for ways to open up treatment processes to families, possibly through Advanced Directives, encouragement of family involvement from the beginning, open treatment team meetings, "Family Days" in treatment facilities, and to encourage consumers to have their families or primary support persons/ groups involved in the treatment process. In summary, everyone agreed that a person in recovery should be embedded in a primary support network. For most, the family could be the primary support if they were actively included in the treatment process.