

Summary of Group 1

Session #1: How we talk to one another: Effective Communication

Family Members

- The terms we use can be barriers. We need to ask for clarification.
- It feels like we are “walking on egg shells”
 - Afraid to say something that will offend
 - Afraid to be considered “over-involved”
 - Afraid not to do enough and resulting damage/pain
- When talking with Providers.....
 - How can we communicate?
 - What can we talk about?
- We are often not offered any resources, very infrequently not involved in treatment
- Families can be supported even when the individual doesn't permit family treatment
- Families need support, education, and treatment
- Family members have no single point of contact in the system, don't know where to start
- We need to find ways to systemically involve families in care
- Family members are typically not linked to resources for a LONG TIME
- Providers need to get permission to involve families at start of inpatient or outpatient care
- If permission is denied, keep asking until family can be involved
- Families need an advocate to help guide them (family advocates in cancer treatment helpful)

Providers

- Often there is no family and sometimes we generalize this to everyone we serve.
- We are trained to provide services predominately in a individual format
- Many providers do not have the skills or organizational support to engage families
- Payment systems tend to favor individual formats of treatment not services to families
- We often feel caught in the middle between the individuals wants and families wants
- We often find it very difficult to get permission of the individual to involve the family
- Often there is a lack of coordination and lack of communication in provider systems

Individuals Served

- Afraid to get help based on a previous bad experience. Families often start help process.
- Most laws/regulations focus on inpatient care, emphasizing the rights of the individual
 - Impact of Civil Rights
 - MH Procedures Act
- Changes in laws and regulations in the '70's reacted to abuses in the 50's
- I wanted my family more involved in care.
- My family was not involved in treatment
- My family was not involved in discharge planning. I kept going in and out of hospitals.

Session #2: The roles we play: Information Exchange

Family Members

- I have to be careful of being too involved, enabling, enmeshed or undermining the plan
- What is the family members role
 - Should I/we be letting go
 - Should we be setting boundaries
- My role is to be a supporter when my son/daughter is not recognizing their mental illness
- It is my role to be assertive with the provider, to make sure my son/daughter get the best care
- My role is to be supportive even though I am grieving the loss of my child over and over
- Role as facilitator and provider of structure.
- Role as an advocate, assuring that providers are able to get help, supervision, consultation

Providers

- I can't share information, even when I think it would help both the family & individual
- It is important to realize that I am not "just my role as _____"
- I am limited to a role as provider by regulation, professional discipline and agency expectations
- I/we need to be able to get support or help when we are stuck

Consumers

- Roles change for the individual over the course of recovery
- Realizing I am not "just my diagnosis" is an important step in recovery
- Too often we participate in self stigma
- I have to be careful what I say as the provider often feels they "know best".
- Once I accepted my mental illness, I took the role of an informed/assertive person in care
- I expect my family to help me even when I don't want it
- Role as an advocate, assuring that providers are able to get help, supervision, consultation

All

- We all play different roles during the recovery process
 - Teacher
 - Advocate
 - Supporter

Session #3: How decisions are made: Control and Responsibility

Family Members

- SB 226 for Assistive [Assertive] Outpatient Treatment would expand treatment options
- Family Members often feel powerless, no say in decisions
- Who is in control when treatment is minimal or service is in private practice?

Providers

- Current laws empower MD to drive involuntary inpatient/outpatient care decision
- A consumer in an intensive service may perceive control is held by the program
- We need to involve families into treatment network to help share decisions
- Involuntary inpatient decisions are sometimes driven by concerns about liability
- Program will describe expectations and responsibilities of both consumer/provider so it is a shared responsibility

Consumers

- In the beginning of treatment MD made 100% of decisions, now it is 50%/50%
- When 100% of the power is in the MD's hands, this contributes to games being played

Summary of Group 2

Session #1: How we talk to one another: Effective Communication

- “Sometimes the stigma is overwhelming.”
- “Doctors won’t listen to families. We are excluded from the communication.”
- “Of all my doctors, my psychiatrist treats me with the least amount of respect.”
- “Providers can be paternalistic. They see what the other doctors have said and then they don’t re-evaluate people. This needs more dialogue between the doctor and the consumer.”
- “The huge amount of weight gain was a surprise to me.” This was also expressed by a parent regarding a weight gain of over 100 pounds for the child.
- “Bad side effects, like morbid obesity are ignored. People should know about them ahead of time.”
- “Without communication people are not treated as individuals. They’re just treated as diagnoses.”
- One doctor had fears of overwhelming individuals with all the facts about all the medications being prescribed.
- “Doctors don’t listen to what is actually happening in a person’s life. They just prescribe more and more medication. They increase the dose and also add another drug if there are any problems.”
- One individual in recovery expressed frustration that her/his family member kept wanting her/him to “snap out of it”, “go to Jesus, listen to more gospel music and forget about it”. “This made me angry and then there was a breakdown in the whole family communication—they stopped supporting me when I got angry with them. Everybody got too frustrated.” This person said it would help if family members were educated on “how to actually be supportive”.
- Several people in recovery expressed how well being assertive with doctors had worked for them. “I require my doctor to listen to me or I get a new doctor.”
- “There is not enough time spent with the doctor. I get about two minutes. He asks how are you and I say fine whether I am or not.” The rushed environment isn’t conducive to honest communication.
- “If you say “No, I’m not fine.” they just increase the medication or add another medication.”
- “Don’t they have a responsibility to make an environment where you can talk about what’s up?”

Session #2: The roles we play: Information Exchange

- Most of this discussion centered on the word stigma. Over and over again the word was used to describe situations from all three viewpoints.
- One consumer/advocate said “consumers can’t do it on their own they need advocates to do it for them, (one example given: filling out forms)
- One medical student said the doctor’s “should have all the control because they have the ultimate responsibility”.
- Family members and providers expressed feeling protective of those in recovery. Sometimes this led to feeling frustrated and resentful when advice was not followed or blame was placed for not advising when advice was forgotten.

Group 2

- It seemed to be the general consensus that community psychiatrists were more recovery focused than private and private practitioners had more autonomy with the amount of time they spent with patients.
- More than one parent expressed their role as protectors as well as teachers and guides.

Session #3: How decisions are made: Control and Responsibility

- Both parents and providers expressed frustrations with and fear for people when they were resistant to advice and treatment that would result in painful, self-defeating behavior.
- Providers spoke of the patience necessary to stay well themselves by protecting their own boundaries. “Everyone involved needs to protect their own boundaries; especially when it comes to exploring ambivalent feelings about any kind of treatment. You have to discover the true desires of the person and then weigh the real costs and benefits of medications and program involvement.”
- “No matter what people do, it sometimes is the illness that is in control. Everyone needs to know that.”
- “It takes patience on everyone’s part during those times”
- “It takes patience and acceptance of the person suffering.”
- “And the people suffering include the parents, siblings and spouses who feel helpless when the disease is in control.”
- “The doctor has to have the control because they have the ultimate responsibility.”
- “Holding the prescription pad with all the accompanying life-changing side-effects and the success/failure rates is overwhelming and sometimes frighteningly intimidating”, a young doctor reported.
- “There is only one person really in control and that’s the person in recovery.”
- “It doesn’t matter how hard anyone works, the real control and responsibility is with the one in recovery.”
- “Everyone involved needs to take care of their own wellness and growth—that is the best way to be the most effective and the most supportive.”
- A significant discussion about the closing of Mayview State Hospital closed the third session. The predominant emotion expressed from all three viewpoints was fear. This fear was centered on the community not being ready for the closing. Providers and service users expressed that services were far below adequate now. With more people coming out to the community and no one going into the state hospital the community services would be completely overwhelmed. Some thought that community hospitals would be overwhelmed. Others expressed fears that they wouldn’t be utilized enough. Community providers and service users had the highest expressed emotion.

