

Minds on the Edge Moderator Report – Group 7

Group Number: 7

Moderator names: Carole Cohn and Joan Davis

Group Description:

The group had 11 participants in our group; 6 male and 5 female, hailing from Philadelphia, its suburbs, and New York. A few were consumers themselves or parents of mentally ill children. Most of the participants were mental health professionals, including a Penn Psychiatrist, a Clinical Psychologist, and a Crisis Intervention Training (CIT) Coordinator, with representation from Horizon House, New Start, Impact Veterans Services, NAMI, NARSD, and Scattergood Foundation. Their deliberation was open and direct, equally sharing personal tragedy and professional wisdom. The vote on “top issues” revealed overlapping concerns around care-giving. The 3 small groups tackled the problem in unique ways, but their conclusions had the following common threads:

- Success comes from integration of family and professional care-givers
- Prevention goals need more attention
- The recipe of services should be based on Consumer need, not cookie-cutter
- Information is critical to success – universal themes included disease education, directory of resources, and access to medical records [despite HIPAA regs.].

The group introduced themselves, noting the following powerful or significant moments from the film *Minds on the Edge*:

- Olivia’s case & the difficulty balancing needs of family and consumer.
- The sheer frustration - trying to solve problems, yet it’s difficult to get patients to agree and “get off the track”.
- That we don’t know yet how to recognize symptoms, and allow people to get too sick before it’s noticed.
- Would like to see more on University services and also a case study that includes Veterans services.
- People cycling back into the street.
- James wasn’t able to get help soon enough; his wife didn’t seem to be involved.
- Seeing them take 2 steps forward and 5 back; how to get them out of the cycle.
- Hopefulness in that Philadelphia is training police in Crisis Intervention.
- Ellen talking about her terror.
- The Dad, on the verge of tears, describing his son living under a bridge.

Policy Issues Identified

Reflecting on the film, the group identified the following underlying policy issues: (Vote counts are included as an indication of each issue’s “importance”. * indicates a Top Issue as determined by the group vote.)

- Helplessness experienced by patients and caregivers in the family and in the field.
- Family Involvement. (6 votes *) The presence or absence of a family support structure impacts the consumer’s ability to cope and navigate the care system.
Sub-topics:
 - How can the family role be integrated with consumer services?
 - How do families find out what resources are available?

Minds on the Edge Moderator Report – Group 7

- Lack of Public Education. (5 votes) Public misunderstanding of “the terror” that patients deal with. There needs to be a move toward community empathy; a general ability to comprehend the biology of the disease and long term impacts.
- Getting medical support to stay healthy. (2 votes) The support system must help caregivers and consumers understand the medical requirements when patients are released.
Sub-topic:
 - We must acknowledge that mental illness is different from other diseases and requires long-term support.
- Process Should Not End. (6 votes *) Follow up is needed to connect consumer services after hospitalization. The group again highlighted care-giver support as a sub-topic, noting “compassion fatigue” experienced by care-givers.
- Emphasis is too clinical when communicating about mental illness; i.e. use of pathology terms. (3 votes) There needs to be more education on what is truly experienced by the consumer.
- Fragmented Services. (8 votes *) It’s difficult to access services, and when services do engage, there is no holistic view of what’s going on with the consumer and the patient’s care. Noting that consumer needs vary, customized service packages are needed.

Then giving consideration to mental health issues in Philadelphia and the surrounding region, the group identified additional issues of importance locally:

- Absence of treatment options. (2 votes) There are no hospitals for treatment, and patients fall through the cracks diagnostically. Lack of beds causes delayed care.
- The care situation is worse for those who don’t have financial support.
- There are regional variances in available services and quality of care. (1 vote) One participant reported being informed by a medical facility that patients can’t cross territory lines. Another participant countered that there is no restriction, they were misinformed.

Top Issues For Analysis

- A. Fragmented Services.
- B. Family Involvement.
- C. Process Should Not End.

Issue-by-issue analysis

Issue Name A. Fragmented Services.

Success

- A point person helps to integrate services / coordinate help.
- There are better education opportunities for family and community.

Minds on the Edge Moderator Report – Group 7

- As a result, Consumers experience reduced hospitalization and better quality of life.

Key Obstacles

- Lack of comprehensible education. [connected to the issue with *clinical emphasis*]
- Over-concern with privacy / confidentiality.
- Stretched resources.

Key Assets

- People who care.
- The money is there – tertiary care -> 1° prevention.
- Nurse Practitioners vs. Doctors.

Actions [*Actors not identified*]

- Apply more resources toward educating the community.
- Collect and distribute data on prevention.
- Early diagnostics for self-awareness and the possibility of a “normal” life.
- Allocation of resources to study successes.

Issue Name B. Family Involvement

Success

- Family understanding and involvement that’s active.
- Redefinition of “family” (i.e. defined by the individual) enabling access to medical electronic record.

Key Obstacles

- Requires empathy from family members.
- Privacy concerns when family history is being discussed.
- Reluctance to share medical history due to stigma of mental illness, past or present.
- Over-load of stresses on a family today [connected to the issue with *Helplessness experienced by patients and care-givers*].
- Potential HIPAA constraints on access to medical records.
- We have no hospitals.

Key Assets

- NAMI
- Family-to-Family training

Actions [*Actors not identified*]

- Modify HIPAA to streamline information access for families.
- Bring more training and involvement to both family members and care providers.
- Work toward a centralized medical record.
- Create a “Concierge” system – mental health services database.
- Implement an independent agency that rates facilities.

Issue Name C. Process Should Not End

Success

- A supportive Community
- Maslows “Hierarchy of Needs” is fulfilled for Consumers
- Extended aftercare services (connected to the issue with *Getting medical support to stay healthy*)
- Consumers are offered employment education

Minds on the Edge Moderator Report – Group 7

Key Obstacles

- Finances
- Lack of education
- Lack of family support
- Lack of housing
- Lack of insurance
- VA connections upon discharge from service / duty

Key Assets

- Crisis Intervention Team
- Outreach; i.e. Mobile Emergency Team
- Homeless Outreach
- Support groups (e.g. Family Resource Network (FRN))
- Veterans Administration
- Survival organizations, advocacy groups
- Hotlines

Actions

- Implementation: provide more, ENDLESS, funding.
Resources (Actors) include Governmental, City, County, State, Community, Family, Advocates for self-sufficiency & employment, Mental Health Organizations, Media outreach, educational organizations