



## **Consumer Quality Initiatives, Inc.**

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# **Family of Mentally Ill Focus Group Report**

## **INTRODUCTION**

The Massachusetts Department of Mental Health (DMH) contracted with CQI to conduct a series of focus groups with adult and youth mental health consumers and family members across the state to help inform their Unified Behavioral Health planning process.

One area of interest for DMH is learning about the experiences of family members of adults with mental illnesses. This report presents common themes that arose from a focus group with family members on their experiences with the mental health system.

## **EXECUTIVE SUMMARY**

- Participants felt that information about DMH and services should be easy for families to obtain. They also wanted providers to do a better job about informing them about their family member's diagnosis.
- Participants felt that all families could benefit from peer support.
- Participants felt that respite was a valuable service for their family members.
- Participants felt that DMH programs require significant oversight, particularly group homes.
- Family members want the opportunity to participate on human rights committees.
- Participants identified the most important service gaps as peer support, socialization opportunities, and support for the transition to independent living situations.

## **FOCUS GROUP PARTICIPANTS**

CQI conducted a focus group with families of persons with mental illnesses on April 20, 2006. The group consisted of 18 participants, 3 male and 15 female, who were part of a NAMI support group. There was some multicultural representation, though a majority of the participants were white/Caucasian.

## **THEMES**

### ***Access***

Persistence was seen as critical to getting the most out of DMH. Most participants stated that they had not known how to attain DMH-eligibility for their family member, and then they got frustrated trying to navigate the system.

Participants felt that information about DMH and services should be easy for families to obtain. Families often made initial contact with the mental health system at hospitals. They felt that hospitals, as well as community organizations, should have a list of key state phone numbers available for families to make initial contact. Others suggested having social workers go into a family's home and help them get connected to services/supports in the area.

Participants reported on the need for an improved method for providers to inform families about the consumer's diagnosis, and then for providing support. They wanted hospital staff to spend more than a few minutes with them, and then offer a referral to a support group like NAMI.

### ***Peer Support for Family Members***

Peer Support for families was identified as a critical need, especially upon learning of a family member's diagnosis. Families need to meet other families who have similar problems for both support and information.

Participants were concerned that families aren't aware of their need for support and the impact a diagnosed illness will have on their lives. They felt that DMH and the system (e.g., hospitals) should work with the family on these issues, and help them access support groups (e.g., NAMI), currently a complex and daunting task. They felt it was important for providers to sponsor support groups, perhaps on a weekly basis as CHL does.

Participants also expressed an interest in an organized annual (or more frequent) event where entire families can meet to socialize. Going out in public can be stressful since they don't always know how their family member will act, so this kind of event could provide a non-threatening social outlet and provide support for both family members and consumers.

### ***Emergencies, Need for Respite Services, & Peer Support***

Many participants commented on the need for information and practical help on a 24/7 basis in case of emergency. Participants suggested having a crisis line staffed by trained nurses, who could evaluate a situation and provide direction. (Their experience with 911 is that the person ends up in jail, rather than getting the support they need.)

Family members felt that people shouldn't have to be hospitalized to access care and services; other states (e.g., New Hampshire) have emergency respite, run by peers who can connect with and support clients. This service provides clients with one on one support when they are in need, in a non-threatening environment.

### ***DMH Group Home Issues, Staff Qualities and Person-Centered Care***

Most participants expressed strong concerns around DMH programs, in particular, group homes. One participant stated, “*They (staff) want you involved, but they don’t involve you in the process.*” Most participants felt that as long as you agree with staff, they want you involved in the process, but if you disagree, they exclude you.

Participants also expressed issues around the rules at group homes, stating they can be too severe, too rigid and not focused on clients’ needs. In general, they feel they are not focused on individualized treatment. Participants stated that staff often misinterprets a client’s behavior because they don’t truly know the individual.

Participants also felt that staff should have “clinical competency.” They said that staff needed better education to truly understand what clients are experiencing. Recommendations by participants included having mental health workers take a course regarding medications, illnesses, and behaviors to become “certified” before they start in the field.

### ***Information on the System and Provider Oversight***

Family members would like information about how services are operated and function (e.g., how money is supposed to be spent). This information would ideally include program specifications, staffing requirements, services to be offered, staff experience, and training requirements.

Participants felt that DMH should do a better job monitoring services on a regular basis, with “spot checks” by someone not affiliated with DMH. They felt that performance standards should be met or exceeded and paid according to the quality of care offered.

### ***Human Rights Concerns/Issues***

Many family members said that there should be DMH and provider Human Rights (HR) Committees that they could participate in. NAMI members reported that they were not able to participate on these committees despite their best efforts. (NAMI members used to be on these committees, but not so much anymore).

Participants felt that their participation was necessary to assure that the committees are impartial and objective. Participants stated that Human Rights officers are typically affiliated with DMH or the provider, so they’re not impartial. The consensus of the group was that Human Rights officers should be someone outside of the program.

### ***Gaps in Services***

Participants felt that the service system had several key gaps for their family member. They wanted more consumer peer support, socialization opportunities, and support for the transition to independent living situations.

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