



Consumer Quality Initiatives, Inc.

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Rural Focus Groups 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 the experience of mental health consumers in rural areas. This report presents common themes that arose from two focus groups with adult consumers living in rural areas on their experiences with the mental health system.

EXECUTIVE SUMMARY

- Consumers in rural areas were universally concerned with the lack of transportation, including the challenges presented by public transportation and MassHealth funded rides.
- Participants believed that they had limited access to mental health services, and in particular wanted more peer support and respite programs.
- Many participants were concerned about the lack of available health care resources, particularly diabetes services, dental care, and eye glasses.
- Most participants were concerned that there was not enough housing in their area.
- Community and family members played a significant role in consumers' well-being.
- Participants were not all that knowledgeable or interested in telemedicine (health care assistance via phone or internet).

FOCUS GROUP PARTICIPANTS

We conducted two separate focus groups and our information was analyzed across the groups.

The focus group in Western Massachusetts was held at the Green River Clubhouse in Greenfield on April 20, 2006. Twenty-five (25) to thirty (30) consumers participated in the group. The majority were Green River Clubhouse members, and the rest were from day rehabs in Greenfield and Athol/Orange. There were more women than men, and most were white/Caucasian.

The focus group in Central Massachusetts was held at Crossroads Clubhouse in Hopedale. There were five (5) participants – three (3) female and two (2) male. All were members of Crossroads. Most were white/Caucasian with one African –American participant.

COMMON THEMES

Transportation

Consumers in rural areas were universally concerned with the lack of transportation, which impacts all other issues (e.g., getting medications, getting to medical/MH appointments, shopping, housing, and employment). DMH consumers usually do not have access to an automobile and thus are reliant on public transportation, their programs, and/or friends.

Participants said that there is no “real” public transportation. At best, there were only a few buses available, which can be unreliable. For example, the Franklin Regional Transit Authority has limited bus runs only to hill towns during school year. If you’re late getting to a psychiatrist appointment, you may not be able to see the psychiatrist because the slot is for 5-10 minutes and they have other appointments.

MassHealth funded transportation (PT-1), which a local transportation company coordinates, is available for medical appointments and some rehabilitation services. However, it can be difficult to access and is not always on time. For example, someone waited three (3) months for their PT-1 application to go through for rides to the clubhouse.

There is limited taxi service available (which is expensive anyways). There is none available in Hopedale, so you have to call a Milford/Framingham service and this becomes very expensive.

Participants reported that Clubhouses provide transportation to and from that program and sometimes for doctor’s appointments. However, they were concerned that the cost of a program’s providing transportation would result in services being cut and staff salaries lowered.

Availability of Behavioral Health Services

In general, participants believed that they had limited access to mental health services. While the emphasis for each region was somewhat different, respite and peer support emerged as two common needs. Also noted are needs that were specific to different geographic locations in Western Massachusetts.

Respite and Peer Support

Participants felt that there should be a greater availability of respite beds. They were concerned that emergency services teams are sending people to the hospital or detox because there is no space in respite.

Participants felt that there should more opportunities for organized peer support. As one person noted: *“It really helps to have peer support when you visit the psychiatrist in times of unwellness. Someone to hold for you the vision and image of who you are, your goals, your wholeness.”* Several participants felt they got this at the clubhouse, but wanted more, and were concerned for the people who could not make it to the clubhouse or were not DMH clients. Another example of good peer support available was the State hospital bringing in peers to talk to patients. Also, participants at the CQI focus groups exchanged of information among peers about topics such as affordable or free health/dental care and about eligibility for shelters and respite, an unintended result of the groups. This demonstrated the peers were a helpful source of

information for other peers and that consumers were in need of information sharing opportunities.

Participants had specific recommendations for DMH. They believed that DMH should start up a program to teach peer support and also run social activities (e.g., dances) to all mental health consumers, not just DMH clients.

Specific Needs by Area of Western MA

Each area had its own specific needs. Participants from the Franklin area noted that there were no teaching hospitals and research centers, perhaps explaining the lack of psychiatrists. Many from the Franklin area were struggling with vocational assistance and getting jobs. People reported being hindered by their low income, resulting in a lack of decent clothing, as well as presentable eyewear and teeth. Vocational training programs were a distance away (i.e. Amherst) and there is job scarcity and prejudice.

Participants in the Athol/Orange area reported that the only psychiatrists in the area are at Community Support Options and Carlson outpatient clinics and both agencies require that you meet with a therapist at their clinic to get psychiatry services (which people objected to).

Participants in the Hopedale group were concerned that the closing of State Hospitals required more community services. They would like to see more slots or additional programs. They also wanted help with financial planning and budgeting, and did not know where to get that assistance.

Availability of General and Specialty Health Care

Many participants were concerned about the lack of available health care resources. As one person said: *“Just because we have a mental illness, we have to be stuck in a hole. We can’t get what we need to get a job and be more self-sufficient.”* Several reported that specialists are a long distance away. Particular issues were addressed in more detail:

Diabetes

There is a significant rate of diabetes among people with mental illness, but participants did not feel that the mental health system was dealing with that reality. While some of the atypical antipsychotics are associated with both weight gain and diabetes, neither programs nor psychiatrists are offering alternative treatments or ways of dealing with the problem. In particular participants felt it was important to get help with diet, exercise, and nutrition. They felt that these wellness activities could be part of case management or a separate program DMH could offer.

Dental Care

People were strong in saying that if there is no dental coverage, other aspects of life (employment, self-esteem, medical health) are negatively affected. They said that there were very few dentists who took MassHealth, and then you had to wait six (6) months to one year for an appointment.

Eyeglasses

People were also very concerned that there was no MassHealth coverage for eyewear, impacting the ability to get a job and socialize.

Housing

Most participants were concerned that there was not enough housing in their area. They reported that the section 8 program is basically shut down, that you can't even get on the waiting list, and that those already on it have a wait of 4 years. In addition, most rents are above subsidy allowance.

People in the Hopedale area said that there are vacated factories that could be converted into low income/disability housing.

Participants in the Franklin group were concerned about the rate of homelessness in the area. In the Franklin area, people knew of 4 shelters. They said shelters and emergency housing were available for women with children and for victims of domestic violence, but there are otherwise no "women-only" shelters. Other services are also more available for single mothers and for women who are survivors of domestic violence.

Community Members and Families

In Western Massachusetts, community members (much more often than providers) were mentioned by many people as helping them get to the doctor, helping them go to an interview, giving them a car, offering a ride or helping with some critical step toward doing better. They helped consumers access what was needed. It can be difficult to rely solely on family or friends for all of your transportation needs.

Telemedicine

Telemedicine, such as offering health care assistance via phone or internet, is now being studied as an intervention in rural areas. In general, participants did not have much interest in this service as an alternative to in person contact. People generally said that it couldn't be a replacement for in person therapy, though possibly as an adjunct support.

One person said she depended on face to face interaction, seeing a therapist's face and reaction, body language. She would not feel safe talking to someone over the phone.

This was the general consensus of the group.

Person-Centered Care

We asked participants to talk about their understanding of and experience with "person-centered care." Participants reported hospital patients are not typically very involved in treatment decisions, which some said could be reasonable if the patient is not well enough to make decisions. State Hospitals, much more than private hospitals, focus on the needs of the person; private hospitals don't try to understand the person, as they are just trying to stabilize and move people on. Several said that they wanted more responsibility for decision making in general.

Participants said that staff should try to involve the consumer in making decisions and not just assume that the client is unable to understand things. Several said that even if one is not making the decisions, staff could do a better job communicating why decisions are being made. That is,

they should tell you what is going on and *“don’t treat you like you’re just a shell or dead.”*
Many were looking for patient-staff collaboration: *“Help us work as a team to get you well.”*

Individualized care also requires the psychiatrist/staff to really get to know his/her client; in this way, s/he will be better able to differentiate between that person’s normal everyday behavior and other kind of behavior. This means that the clinician should probably spend more time with the clients when they first meet or are admitted. Representing the views of others, one person said: *“What’s right for one, is not necessarily what is right for another. They shouldn’t cluster people together based on diagnosis.”*

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