



Consumer Quality Initiatives, Inc.

132 Kemble St.
Roxbury, MA 02119
Phone (617) 427-0505
www.cqi-mass.org

Adult Recovery-Oriented Care 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 recovery-oriented care. This report presents common themes that arose from two focus groups with adult consumers on the topic of recovery-oriented care and their experiences with the mental health system.

EXECUTIVE SUMMARY

- “Recovery” for our participants meant having societal roles that promote achieving independence, being active, and feeling better.
- Participants said the following elements were necessary (though not sufficient) to a recovery oriented program/system: 1) Prevention through education and outreach, 2) Consumer-centered, strength-based care planning, 3) Significant involvement of consumers in treatment planning, 4) Respect, 5) Self-determination, 6) Qualified staff, 7) Peer/social support and 8) Advocacy assistance.

FOCUS GROUP PARTICIPANTS

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

The focus group in Western Mass. was held at the area office in Northampton on April 11, 2006. There were 12 consumer participants, with equivalent gender representation. There was some multicultural representation, though most participants were white/Caucasian.

The focus group in Southeastern Mass. was held at DMH offices on the grounds of Taunton State Hospital on April 13, 2006. There were 13 consumer participants, with equivalent gender representation. Most of the participants were white/Caucasian.

We covered two topics. We first asked participants to define recovery. We then asked them to describe the values and activities of a recovery-oriented program and system.

QUESTIONS

A. What is recovery?

Consumers were first asked to define recovery in the mental illness context. Their responses fell into three categories:

- 1) Achieving established societal roles that promote independence, including employment, having one's own home, and school.
- 2) Being active. Comments included:
"Doing good things for myself, taking a walk in nature"
"I can go downtown, get out of the house"
- 3) Feeling better. Comments included:
"Not being worried, hurting and sad all the time"
"Functioning at a point to feel happy"

We also asked people what it meant to be "*recovered*", and almost everyone talked about "*knowing*" and "*managing*" the illness. One person described it as, "*An ongoing process that doesn't end.*" A few people talked more about outcomes, with one person saying: "*Living in the least restrictive alternative.*"

B. What elements and values do recovery-oriented programs and systems contain?

Participants were asked to talk about the kind of system/program that would promote recovery, i.e., a recovery oriented mental health program/system of care. The concept "recovery-oriented" has no fixed framework, so it is important to tap into the knowledge and experience of consumers. Through these two focus groups, *eight* themes were identified as necessary for a recovery oriented system, though this list should not be considered exhaustive. These elements are:

- 1) Prevention through education and outreach
- 2) Consumer-centered, strength-based care planning
- 3) Significant involvement of consumer in treatment planning
- 4) Respect
- 5) Self-determination
- 6) Qualified staff
- 7) Peer/social support
- 8) Advocacy assistance

COMMON THEMES

Prevention through education and outreach

Many of our participants became eligible for DMH services only after they were brought into the system through incapacitation (i.e., admittance to a State Hospital), homelessness, and/or criminal justice involvement (e.g., jail/prison). Participants felt that people should have an opportunity to enter into DMH treatment before they suffer to a degree that their lives go totally downhill. They thus recommended prevention through outreach and education.

Participants felt that the public needs to be educated about mental illness and how to get help for it. For example, the public should be informed that there is no need to be afraid of someone acting strange or to judge a person by such actions. The public should not be afraid to call for help for themselves and their family, and it is important for the public to know who the DMH contact people are.

In particular, participants felt that schools (e.g., school psychologists) should educate students and teachers about the signs of mental illness and available treatments. This education would provide students with the capacity to get help before problems became overwhelming.

It is also important to outreach to people who are homeless or in the hospital. Comments included:

“They should have someone reach out to you and ask ‘what do you need?’”

“There are not enough people telling me there are answers to these problems, telling me what is available. I waited 10-15 years. ”

Consumer-centered, strength-based care planning

Participants uniformly agreed that programs and systems should be developed to meet the needs and desires of people with mental illness, not just those of providers. They noted that consumer-centered services require providers to:

- Focus on the person in a holistic manner, not just as a case or illness. As one person noted, *“Do not dwell on the illness”*;
- Find out what’s on people’s minds and what they really want to do. One person noted that it *“should be the consumer’s objective, not what fits into the clinician’s framework or formula.”* They noted that providers/clinicians should not make decisions for them;
- Not apply rules indiscriminately. Several talked about being forced out of their group home during the day, even when sick. If a *“person is paying rent, they have a right to make decisions, and not to force people to move too fast, like telling you when to work”*;
- Recognize that people have a right to their opinions, which should be valued. As one person noted: *“There should be a format where we can write down our strengths and talents”*; and
- Proceed at the pace of the person, not what is needed programmatically. One person noted this as *“the freedom to change.”*

Significant involvement of consumer in treatment planning

All participants said that it was critical for a person to be involved in and contributing to their treatment and other planning. We heard a familiar refrain from consumers: *“How else would you learn how to take care of yourself and become more independent.”* Another noted: *“I don’t see*

any other way. *If you don't participate, you don't get better.*" Consumers want to participate fully in their care.

A significant component of person involvement was being treated with **respect** in the treatment and planning relationship (see also section (4)). Participants were largely focused on the importance of staff listening to them and that information being integrated into their plan. They also wanted the opportunity to make changes during the year, even before there is an annual date to review the ISP¹. Some noted instances in which staff wrote out a plan without the consumer's involvement and then asked them to sign it. One person noted: *"I may be wrong sometimes and right sometimes, but I want to be respected either way."*

Several consumers were pleased with their level of involvement, but were concerned that people who were less articulate or expressive might not be so involved. As one person noted: *"To get it done faster, you must participate, take a leadership role."* Another person who was concerned about cultural competency issues said: *"They need to be more friendly to people of different backgrounds, such as foreigners."*

Respect

This theme was mentioned with such commonality and strength, that it deserves special mention here. "Respect" acknowledges the person as an individual and not just an illness or a case. The treatment plan is here more than something on paper, but a living document attached to a life.

Another aspect of respect is safety, as referred to by a participant as *"Do no harm... like in medicine. Staff need to keep that in mind, that it's better to do nothing than to do harm."* Participants also noted that although coercion may be something that needs to be done, that it should be done "respectfully." Consumers who are coerced/restrained should be told why it happened and what can be done to avoid it.

Another aspect of respect is fairness- *"Treat everyone equally."*

Self-determination

Self determination in this context refers to "the right of consumers to make individual decisions or choices about all aspects of their recovery," including desired outcomes, preferred treatment and services, and when to start and stop treatment².

People talked about this concept in a variety of ways, but the strongest theme was *"freedom... to get out on my own."* Underlying the freedom principle is the need for *"independence."* In fact, participants noted that they needed *"space to recover, to be free to come and go... that getting out of the house is essential to recovery."* Several participants felt that even when they become independent, DMH should *"always be there if they fall,"* and that programs should be available *"at crisis moments."*

Participants noted that a certain foundation needed to be in place for most people to enact self-determination. Elements of that foundation included:

¹ Individual Service Plan

² BUCPR

- Advocacy training, to express your views and opinions, for both consumers and families. Several mentioned the M-POWER³ self-advocacy trainings.
- Education on rights and ways to use the legal and human rights system. They said that written materials alone are not sufficient for good learning; interactive educational meetings are also needed.
- Attorneys are often needed to help with basic freedoms (e.g., right to choose medications), the right to health care, and with social security.
- Free and easy access to residential services, medical insurance/care, housing (subsidies). It is difficult to take leadership in your life when your basic needs are not being met.
- Opportunities for employment, a great way of raising self-esteem. As one person noted, *“When you’re working, your mind is focused, thinking about your job.”*
- Basic “skills training,” particularly in cooking/food. Some of these people did not feel they were getting that in their group homes.

Qualified staff

Participants felt that not every person is capable of being staff in a recovery-oriented system. In general, they felt that such staff needed to:

- know about mental illness and mental health;
- be of good character, not the kind of person who engages in “baiting” (e.g. provoking or harassing);
- have the capacity to offer hope, which can be as simple as saying the right thing; and
- have a positive focus.

Peer/social support

For a recovery oriented system, peers are important to offer the following:

- Support (e.g., groups)
- Friendship and relationships (e.g., trips, card games). As one person noted, *“I have friends I made in the mental health system, peers, I’ve kept in touch over the years. That is VERY helpful.”*
- Information (e.g., about medications, supports)

Advocacy assistance

Participants felt that at times when they had difficulties with providers or the system, they might need an outside advocate. This may come in the form of a human right officer, but they also wanted access to an advocate outside of the system, such as a peer.

For more information, contact Jonathan Delman, 617-427-0505, jdelman@cqi-mass.org
132 Kemble Street * Roxbury, MA 02119

³ Massachusetts People/Patients Organized for Wellness, Empowerment and Recovery.