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ADULT SERVICES FOCUS GROUPS SUMMARY REPORT

Prepared for DMH Unified Behavioral Health Planning Process

EXECUTIVE SUMMARY

- In 15 focus groups held throughout the state with adult consumers and family members of adult consumers, participants were asked to discuss their views of the adult mental health system.
- Four broad topic areas emerged from an analysis of the data:
 - Basic Needs;
 - Prevention;
 - Consumer-driven Care;
 - Staff Qualities.
- Among the themes discussed in this report, the themes most emphasized by consumers were:
 - The need for safe and affordable housing;
 - The rejection of program rules that are too rigid, nonsensical, and/or applied arbitrarily;
 - The critical need for more information in general: for the public with regard to stigma reduction and accessing mental health services, and for individuals about available services and navigating a challenging system;
 - Consumer-centeredness is not enough; Consumers not only want the care to be about them, but they also want to be involved in planning their treatment;
 - Good and reliable transportation is necessary to access important resources and is not always available, particularly in non-urban areas;
 - Staff matter, and they need to be knowledgeable and inspiring to matter in a significant and positive way.

INTRODUCTION

The Massachusetts Department of Mental Health (DMH) contracted with CQI to conduct a series of twenty focus groups with mental health consumers and family members across the state. The goal was to inform DMH's Unified Behavioral Health planning process.

In fifteen of these focus groups, participants were asked to discuss their views of the adult mental health system. Fourteen groups consisted of adults with mental illness, and one was made up of family members.

Each focus group had a particular topic for CQI to explore in depth. Thus, several groups were asked to consider specific subject matter, including “recovery oriented care,” peer-operated services, wellness, medical care, and eligibility and access to services. Other groups consisted of a particular population group, including groups with senior citizens, youth in transition, parents with mental illness, people living in rural areas, and Cambodian-Americans. Participants in every group were also asked to talk about several common topics as well: their description of “person-centered care,” continuity and coordination, their service needs, and service gaps in general.

FOCUS GROUP PARTICIPANTS

Fourteen of the fifteen focus groups discussed here consisted solely of adults with mental illness, most of whom were DMH clients. These focus groups included a total of 145 participants. The majority of participants were white/Caucasian, although there was multicultural representation in most groups. Groups were held in all areas of the state.

COMMON THEMES

Although each group focused on a particular topic, strong themes emerged across the groups about adult mental health and services. For this report, we grouped the themes into four topic areas: 1) critical/basic needs, 2) prevention, 3) consumer-driven care, and 4) program and services staff. Each theme we discuss in this report was important to many of our focus group participants. Most of these themes are also discussed in the individual focus group reports.

Basic Needs

Housing

Stable and affordable housing was a central concern for many participants in the adult focus groups. Participants often identified good housing as being fundamental to their independence, recovery and wellness.

Participants shared their struggles with maintaining stable housing, many saying that a crisis in their lives, either mental health or family related, was the reason they had been suddenly faced with homelessness. Having an early intervention when a mental health or family crisis arises prevents much more challenging problems, such as addiction or homelessness.

Homeless shelters were considered crowded, unsafe, and “not taking people anymore”. One person said that shelters were particularly difficult for consumers because, “You

can't get yourself together in a place like that. We got stuff on our minds." Many participants felt that more outreach was needed to the homeless population.

Transportation

Many participants were concerned with a lack of transportation, which impacts all other issues (e.g., getting medications, medical/mental health appointments, shopping, housing, and employment). Participants reported that many consumers usually do not have access to an automobile, and thus are reliant on public transportation, their programs, and/or friends and family. 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.

This was a particular challenge for people in rural areas, where there is no "real" public transportation. At best, there are often only a few buses available, which can be unreliable.

Dental, Medical, and Eye Care

Many participants were concerned about the lack of available medical care resources. The situation was most acute in rural areas, such as Western Massachusetts where there is not a great concentration of wealth or academic medical centers. Several reported that specialists are a long distance away.

Many participants' greatest concern was the lack of good dental coverage and care. They said that MassHealth now covers only extractions, but not basic preventative care. Without dental care, they said that other aspects of their life (employment, self-esteem, medical health) are negatively affected.

Participants were also very concerned that eye care and eyeglasses were not covered by MassHealth. This again affected their rehabilitation and employment prospects.

Prevention

Many of our participants found psychiatric and/or DMH services only after a series of crises brought them into the system. Service access was often driven by incapacitation, homelessness, and/or incarceration or other criminal justice involvement. Participants strongly recommended more preventative services through outreach and education.

Education on Mental Illness and Stigma

Participants felt that the public needs to be educated about mental illness and how to get help for it. They wanted the public to know that people with mental illness can get better, that it's OK to ask for help, and that there can be services available to help them. They felt that DMH should have more of a presence in the community (for stigma reduction, outreach, and education purposes), and have peers as full and natural participants in this endeavor.

Participants also felt that stigma reduction was necessary because the public is quick to make judgments about all people with mental illness. They wanted the public to know that people with mental illness can get better and are no more violent than other people.

The stigma concern was particularly significant with the Cambodian-American participants, who described the negative perceptions their community has of people with mental illness. Participants noted that it is difficult to reach out for services when community members do not understand and do not believe treatment and services will help.

Information

The need for information came up at most focus groups. Consumers want information about many things, including:

- Seeking DMH service eligibility;
- Navigating a complicated system once eligible;
- The availability of where and how to access resources that address their multiple needs (e.g., medical care, housing, consumer-operated services, transportation);
- Mental illness, treatments, and recovery.

Access to Services

As noted above, participants felt that consumers did not get the help they needed until the situation became dire. Many had not become eligible for DMH services until they were admitted to a state hospital or had become eligible for MassHealth and then had help from a program to become eligible. They wanted a greater emphasis for DMH on educational outreach about how to access DMH and other agency services.

Participants also felt that care coordination and transportation (above) were critical for them to access services and activities. Participants received this kind of help from a variety of people and organizations, particularly DMH case managers, and supported housing staff for some.

Peer Support and Peer Operated Services

Participants overall very much valued peer support. Many liked the idea of peer support groups, and others liked more informal opportunities for peer support, such as through social or physical activities.

Participants saw peer support as an opportunity for networking, personal support for struggles, friendships, and gathering important information about medications, services and other resources. Many had received practical assistance from peers to access services, particularly by getting a ride.

Participants also felt that it could be motivating and encouraging to interact with people who have overcome their struggles with mental illness. One person said he got to see others, *“falling off the horse and getting back on, and that made me fight and want to press on.”* Participants said it was helpful to meet other people who have been in their

situation, as opposed to health professionals, who “*haven’t been on the other side of the street.*”

Participants were very interested in a consumer-led leadership or advocacy training, particularly in relation to an issue they cared about. They also valued peer lead services in that it provided clear examples of people who had gotten better.

Crisis Planning

Participants said they were interested in having a plan in case of a crisis. This would help them stay well in general, and out of the hospital in particular. Several said they were already working in a group setting to identify triggers and plan for crises (e.g., using DBT, Wellness Recovery Action Plan (WRAP)). Some were interested in thinking about a plan, but were less enthusiastic about the seriousness and structure of meeting in a group and writing it down. One said, “*We do it informally. Then you don’t have to nail bite. It’s just natural.*”

Parents who had a mental illness said they needed more support than they had received in planning for a crisis. A significant part of that planning would be identifying placements for the children when a parent becomes temporarily incapacitated. This would remove stress from their lives and decrease the potential for DSS involvement.

Respite

Several participants felt that there should be more respite services. They were concerned that emergency services teams are sending people to hospitals or detoxes because there is no space in respite. Some consumers liked the idea of peer respite programs, because they felt peers could better understand how they were feeling during a crisis.

Wellness activities

Numerous people talked about the need for a more holistic approach to both physical and mental well-being. They wanted a wellness approach. The wellness approach involves exercise, proper eating, smoking cessation, good health/dental care, alternative treatments, good housing, and valid information and advice about medications.

Participants felt that the system’s and providers’ “psychiatric philosophy” focused too much on one’s mental illness to the exclusion of one’s physical health. They wanted more emphasis on wellness throughout the system; they wanted administrators, staff and consumers to talk about it on a day-to-day basis.

Consumer-Driven Care

Rules

Most participants reported that program rules and policies were often rigid and nonsensical, ignored individuals' unique needs, and could be applied arbitrarily. Consumer frustration with this concern was palpable. Participants felt that what is right for one person is not necessarily what is right for another. Elders and those in residential programs were the most concerned with rules because they felt they often limited their freedom and independence. Requirements to be "out of the house" for 5+ hours per day or to attend a program 4+ days a week were not often inconsistent with a person's needs or desires.

Components of consumer-driven care

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. Below are some of the major domains identified by participants as fundamental to consumer-driven services.

1. Person-centered and strength-based. Person-centered care requires that providers recognize the person's right to their opinions and to exercise their strengths, both of which should be valued. Many consumers were looking for better patient-staff collaboration, emphasizing the importance of staff's listening to them, and then that information being integrated into their treatment plan.

Individualized services require staff and clinicians to really get to know their clients. Consumers were interested in staff spending more time getting to know them as individuals. Individualized care requires providers to proceed at the pace of the person, not what is needed programmatically.

2. Person involvement in treatment planning. Participants said that it was critical for a person to be involved in and contributing to their treatment and treatment planning. We heard a familiar refrain from consumers: "*How else would you learn how to take care of yourself and become more independent.*" Person-involvement requires that providers find out what is 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 felt that providers/clinicians should not make decisions for them. Many participants felt that providers in inpatient and community settings, particularly group homes, did not adequately involve them in their treatment planning.

3. Respect. Participants said that staff "respecting" them and their wishes was critical for their recovery. Participants also said that coercion/restraints should be avoided, but if used, consumers should be told why it happened and what can be done to avoid it.

4. Self-determination. People talked about self-determination in a variety of ways, but the strongest theme was "*freedom... to get out on my own.*" People also stressed needing 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.*"

Programs and Services Staff

Staff Qualities

Participants felt that not all people are capable of taking on the responsibilities of 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;
- have a positive focus;
- be empathetic, a good listener and a strong advocate; and
- be relatable, have less distance, and open up on a personal level.

Role of Case Manager

Participants very much valued having a DMH case manager to assist them with identifying and accessing useful services, as well as to discuss problems and to help with rides. Many participants identified their case manager as the first person that they turned to when they had an issue, and many felt that their case manager understood them because s/he helped them access the services they needed.

Many consumers felt it would be okay for them to no longer have a DMH case manager, but only if they no longer needed that assistance, or a private program (e.g., supported housing) could pick up the case manager’s role. Several were concerned that they lost contact with their case manager when they were hospitalized.

DISCUSSION

DMH has many important challenges for the future. The most important challenge is to move from a system that is rooted in a psychiatric philosophy that focuses on treatment and stabilization, to one that utilizes a public health approach, with a strong focus on rehabilitation, recovery, and the development of natural supports in the community.

This public health approach starts with prevention: creating an environment where community members, family, and friends can take steps to avoid the ravages of mental illness and its antecedent effects (egs., poverty, medical co-morbidity). DMH will need to continue to support the further development of peer support groups and services, wellness activities, opportunities to develop crisis and life plans, and respite services.

In a system that values prevention, community members should have an opportunity to get individualized help before becoming so ill they become DMH-eligible. MassHealth provides some basic services, but in times of intense distress consumers may need more comprehensive help, including housing and employment assistance. In addition, a culturally appropriate anti-stigma campaign, in collaboration with consumers, could encourage people in distress to ask for help. As a requisite preliminary step however,

DMH will need to conduct further research on the mental health service needs of different cultural and geographic communities.

Another challenge for DMH is to make sure that consumers' basic needs are being met. Many consumers in our groups were more concerned about the circumstances that could cause them to have a mental breakdown than they were about mental health care per se. Most consumers felt that without safe and affordable housing, they were in real trouble. They also needed reliable transportation, particularly in non-urban areas, not only to get to doctors appointments, but to hold jobs.

Consumers also felt that not being physically well and not appearing well had caused and would cause them a lot of problems. Poor dental health and poor eye-wear limited job opportunities and infused a lack of confidence with regard to family events and romantic relationships. Also, having an under-treated chronic condition (eg, diabetes), being in pain, and not seeing clearly not only interferes with the possibilities mentioned above, but also contributes to premature deaths.

In order to provide consistent and high quality care, DMH will need to engage in a significant culture shift. Thus, DMH will need to move from an adult system that is over-reliant on strict rules to one that meets the specific needs of individuals. For example, many consumers, particularly those living in group homes, were very frustrated with rules that seemed to limit their personal growth, rather than encourage it. Elders are already discouraged with their prospects, so to require them to attend a program more than want feels like an assault on their dignity.

There must be an insistence on the significant involvement of consumers in their planning overall, and their treatment planning in particular. As we heard many times, "How else will people learn to both manage their illness and become truly independent?" In this regard, consumers were looking for staff to be collaborators, as well as advisors and helpers. They also felt that staff really need to solicit their input, and take it seriously.

Thus, another challenge for DMH is staff development. While participants had a mix of experiences with staff, they were clear on desired staff qualities. Many wanted staff that would take into account their strengths, and not be so focused on the illness. They had hopes of getting better, and felt that someone with a positive focus and the capacity to offer hope could help them best. Many had met staff that seemed more focused on maintaining a sense of stability, for both the program and the person, as opposed to promoting a sense of growth and recovery.

In conclusion, DMH has several broad challenges. As the public mental health authority, it needs to work with the community and other governmental agencies to meet the basic and prevention needs of consumers. Thus, DMH needs to work in a collaborative fashion, particularly with consumers and family members, whose focus is not the status quo but on improve their lives and the mental health system. In addition, DMH must change from within (including providers it oversees), building a culture that fosters a strengths-based

approach, significant consumer involvement in their care, and attention to the individualized needs of each consumer.

This can be accomplished by bringing the agents of change, consumers and family members, into all critical policy making decisions relating to services, administration, quality management and research.