



Consumer Quality Initiatives, Inc.

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

Young Adult (Transition Age) 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 learning about the experiences of young adults with mental illnesses. This report presents common themes that arose from focus groups with young adult with mental illnesses on their experiences with the mental health system.

EXECUTIVE SUMMARY

- Young adults need information about services in order to participate actively in treatment decisions regarding their care and to help determine what services should be offered by the system.
- Young adults believe that there is an overemphasis in the adolescent system on rules and structure, such that their specific needs are not addressed and they are not prepared for independent living as adults.
- Psychiatrists and program staff (e.g., housing programs) need to be empathetic, well-trained, and have experience working with young adults with mental illness.
- DMH case managers are seen as being helpful with coordinating services, such as housing, school, and other programs.
- Affordable housing is critical for a successful transition to adulthood, though some young adults found it very difficult to find independent housing. Some key qualities of good housing are privacy, safety, cleanliness, and not too many rules.

FOCUS GROUP PARTICIPANTS

CQI conducted two separate focus groups, on April 10, 2006 and May 12, 2006, and our information was analyzed across the groups.

One focus group was held in Westborough with representatives of the statewide young adult steering committee. The group contained 12 young adults, 10 males and 2 females between the ages of 18 and 29. There was some multicultural representation, though a majority of the participants were white/Caucasian.

The other group was held in Framingham with 4 young adults, 3 females and one male between the ages of 19 and 21. Three participants were Caucasian and one was multiracial. The participants in the Framingham focus group were all receiving services through Wayside Family Services.

THEMES

Information and Participation

Young adults need information about services to participate actively in decisions regarding their care as well as systems planning. However, many participants said that they often did not receive accurate information about available services and programs.

They also felt that they knew what kinds of services were right for them, and they wanted to be involved in discussions that lead to service provision decisions. However, participants felt that often their input was not truly valued or respected; many felt that providers just told them what to do, with one person stating: *“They ask for your choice, but they don’t act on it.”* Another person said, *“They didn’t spend time focusing on my thoughts and desires.”*

Some participants did not feel that they had been a true participant in team meetings, which were most often held when they had done something “wrong.” They then felt *“ganged up on”* rather than feeling positive about the team experience.

Rules and Structure and Person Centeredness

Participants reported that youth programs have too many rules and too much structure, thus not preparing them for independent living as an adult. They reported more satisfaction with housing programs that have fewer rules and more individualized treatment.

Others mentioned that they felt individual counseling was not helpful to them, but they still were required to go. They felt group counseling would be more productive, that they would benefit from being with peers and listening to other people’s experiences.

Staff Experience and Attitudes

Participants had difficulties with staff in both the child/adolescent and adult systems. Many participants reported that interactions with staff, particularly at their housing programs, directly affected their well-being. Many said that staff often did not know how to communicate or empathize with them. They were concerned that many staff did not have the experience or knowledge needed to work with young people who have a mental illness. Respondents felt staff needed training around these issues.

Participants sensed that it was difficult to find “good staff,” which they described succinctly as people who are “real, straight up.” Some respondents talked about negative experiences with psychiatrists, feeling that their psychiatrist focused on the problem, but not the person. They also recommended more peer counselors, people who have

experienced similar issues and can relate and understand them, though not necessarily their own age.

Participants said that experiences in the adolescent system often left them with less trust in both people and the system. That is, they were less likely to have open communication with providers in the adult system, and wouldn't necessarily ask for help with their needs.

DMH Case Managers

Most participants felt they benefited from having a case manager, stating that their case manager helped coordinate services and assisted them with dealing with other agencies, such as MassHealth and Social Security.

Some felt that it would be helpful if their DMH case manager could inform them of all of the services DMH offers, what case managers can and cannot help them with, and how DMH works.

Housing

Most respondents said that more affordable housing, particularly permanent housing, was critical for them to get better. Many of those who had transitioned from the youth system into the adult system talked about the need for transitional/temporary housing for those who do not have anyplace to go.

Participants talked about desirable qualities in housing. Qualities included having privacy, safety, cleanliness, and not too many rules. Some respondents talked about having housing that was "*dorm room style*" or "*tent city style-living with 'healthy' people*".

Most respondents talked about how difficult it is to access independent housing, noting the long waiting lists for public housing. Those who were in transitional programs (for a certain amount of time or until a certain age) were concerned about where they would live when the time came for them to leave the program.

Transportation

Transportation was also mentioned by some respondents as a need for young adults. Often they do not have their driver's license or a car and programs typically only provide transportation to doctor's appointments. They stated that it would be helpful to have transportation to assist them with food shopping or getting their medications at the pharmacy.

For more information, contact Jonathan Delman, 617-427-0505, jdelman@cqi-mass.org.