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Elders 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 the experiences of elders with mental illness. This report presents common themes that arose from a focus group with elder consumers living in a group home.

EXECUTIVE SUMMARY

- Many elders felt a loss of independence and normalcy living in a group home, including a loss of privacy, control, dignity to a degree, and skills. Assisted living was preferred.
- Elders wanted more flexibility in the rules, particularly pertaining to day program attendance requirements. They also said that rules were sometimes hard remember, and they did not want to be penalized for insignificant rules infractions.
- Elders wanted to feel respected by their providers.

FOCUS GROUP PARTICIPANTS

The focus group, held at a group home for older people in Lynn, contained 6 participants who lived there. There were four women and two men, most of whom were white/Caucasian, with one African-American.

FINDINGS

Loss of Independence and Normalcy

In general, group participants were very frustrated with their loss of independence, particularly with regard their living in a group home. Many of these participants had lived independent and full lives. In contrast, the group home engenders both shared space and rules, resulting in a loss of privacy, control and to a degree dignity.

Some were discouraged in general. Participants reported that their goals were for “normalcy,” but were afraid of losing skills by living in a group home. They felt that “daycare is OK, not

much of a choice.” They were discouraged that they would be on medications for the rest of their life.

Assisted living (own bathroom with areas to spend time with people and share food) was considered preferable to a group home, but they knew it was more expensive.

Rules

Most participants understood the reasons for house rules, and the challenges of providing individualized care in group settings. However, several felt that rules were sometimes applied arbitrarily. For example, residents might be required to attend a day program 4 days a week, but several would prefer to attend less in order to reduce the intensity of interactions with other program attendees (whom they may not like) and/or to take care of cleaning or other work at home. They felt there should be more “wiggle room” with regard to how often they need to attend a program. That is, they did not believe in “strict” rules, as it does not allow them to always be treated as individuals.

The other thing about rules is that they can be difficult to remember, particularly for elders. Thus, they generally did not believe that people should be penalized for breaking rules.

Respectful Treatment

Participants also described the need for respectful treatment. They don’t want to “talked down to” or ordered around.

One woman sees a psychiatrist who does not make any eye contact with her, but instead looks down and writes notes, even as she enters into the room. She asked him to look at her when talking to her, and the psychiatrist responded that maybe she should find a new psychiatrist. Clinicians and staff need to remember that elders are sensitive to a loss of respect, and treat them as they would other any other human being they cared about.