



## Characteristics and Needs of Newly 508 Certified Consumers

The fifth wave of the LCO study was marked by the inclusion of a new cohort of participants. This new cohort included 101 consumers who were 508 certified for the first time in 1996. In comparison, the longitudinal cohort included 269 consumers who were 508 certified prior to 1991. Analyses were conducted to identify differences between cohorts with regard to demographic and clinical characteristics, needs, and perceptions about services.

According to observations and reports from service providers, family groups, and administrators, individuals currently entering 508 status were expected to be younger and suffer from more chronic mental health problems than individuals in who were 508 certified in the past. The results of this study dispelled some expectations, upheld others and revealed a number of unanticipated differences. These findings are described in the following pages.

### Demographic and diagnostic characteristics

Age. Consumers in the new cohort were younger than consumers in the old cohort (mean age new cohort, 42.4 years; old cohort, 50.1 years). However, they were not as young as expected. The age difference between cohorts was approximately 8 years--equivalent to the number of years since the old cohort entered the study. Therefore, the new cohort was approximately the same age that the old cohort was when the study began in 1991.

Race. There were more African American consumers in the new cohort than the old cohort. The proportion of consumers who were African American was 20% in the old cohort and 26% in the new cohort. Additional analyses of MHIS service records have confirmed that these changes in ethnicity are representative of changes seen in the 508 population statewide.

Marital Status. Individuals in the new cohort were more likely to have been married at some point during their lives (old cohort, 60%; new cohort, 79%). Consumers in the old cohort were more likely to have never married (old cohort, 40%; new cohort, 21%).

### Clinical status and physical health

Diagnosis. The rate of schizophrenia was substantially lower in the new cohort, while the rate of affective disorder was much higher. Schizophrenia was the primary diagnosis for 39% of the old cohort and 13% of the new cohort. Affective disorder was the primary diagnosis for 20% of the old cohort, compared to 54% of the new cohort. Analysis of MHIS service records indicated that this pattern of change occurred statewide.

Symptomatology. According to case managers' ratings of symptomatology, consumers in the new cohort were less likely to experience symptoms of psychoticism ("moderate" to "extreme" symptoms were reported among 37% of old cohort, 26% of new cohort), but more likely to experience depression ("moderate" to "extreme" symptoms reported among 43% of old cohort, 57% of new cohort) and anxiety ("moderate" to "extreme" symptoms reported among 51% of old cohort, 58% of new cohort). According to consumers' self-reports, consumers in the new cohort were more likely to be bothered "moderately" to "extremely" by symptoms of depression (old cohort, 23%; new cohort, 43%).

Quality of Life. Consumers in the new cohort reported a lower quality of life. They were more likely than individuals in the old cohort to indicate that they felt "mostly dissatisfied" or "terrible" about their life as a whole (old cohort, 15%; new cohort, 29%), as well as their leisure activities (old cohort, 8%; new cohort, 24%), physical health (old cohort, 9%; new cohort, 20%), and finances (old cohort, 29%; new cohort, 36%).

Level of functioning. According to case managers' ratings, consumers in the new cohort needed less assistance with daily living (e.g., preparing meals, maintaining personal hygiene) compared to those in the old cohort. Only fourteen percent of consumers in the new cohort needed "minor" to "moderate" levels of assistance with daily living compared to 33% of consumers in the old cohort.

Physical Health Status. Due to their younger age, individuals in the new cohort were expected to have better physical health; however, the results suggest that individuals in the new cohort were more likely than individuals in the old cohort to experience physical ailments that interfered with their functioning. For instance, case managers indicated that physical ailments were "somewhat" or "very" problematic to the functioning of 17% of consumers in the old cohort compared to 24% of consumers in the new cohort. Twenty-eight percent of consumers in the old cohort, compared to 43% of consumers in the new cohort reported that their physical health interfered with their everyday functioning to a "moderate" or "extreme" extent.

### **Criminal justice involvement**

The proportion of consumers indicating that they had been arrested or jailed within the past year was approximately equivalent for both cohorts (old cohort, 6%; new cohort, 8%). However, individuals in the new cohort were more likely to report that they had been victimized at some point during their lifetime: threatened with physical harm (old cohort, 37%; new cohort, 46%); physically attacked (old cohort, 34%; new cohort, 46%), or pressured or forced into sexual activity (old cohort, 24%; new cohort, 30%).

### **Working or volunteering**

In spite of their younger age, individuals in the new cohort were no more likely than consumers in the old cohort to work or volunteer. The proportion of consumers working or volunteering was approximately equivalent for both cohorts (old cohort, 26%; new cohort, 27%). However, consumers in the new cohort attributed more importance to having a job. Forty-one percent of consumers in the old cohort versus 52% of consumers in the new cohort indicated that it was "quite a bit" or "extremely" important to work or volunteer. Individuals in the new cohort were also more likely to receive vocation assistance (old cohort, 6%; new cohort, 14%). Possibly the greater levels of

physical disability and depression make it more difficult for individuals in the new cohort to work.

## Service needs

Individuals in the new cohort had higher levels of need for some mental health and community support services. For example, they reported needing more assistance to deal with upsets and crises, talk about problems and deal with legal issues (see Table 1). They also reported receiving more assistance in these areas (see Table 2).

Table 1. Help needed by cohort

Help Needed	Old Cohort	New Cohort
Upsets and Crises	1.74(1.27)	2.25(1.17)
Talking about Problems	1.94(1.23)	2.32(1.28)
Legal Help	.85(1.26)	1.15(1.37)

Note. Table values represent means (and standard deviations). Scale: 0=none, 1= a little, 2=some, 3=quite a bit, 4=completely

Table 2. Help received by cohort

Help Received	Old Cohort	New Cohort
Upsets and Crises	1.77(1.30)	2.28(1.14)
Talking about Problems	1.75(1.20)	2.19(1.17)
Legal Help	.69(1.21)	.94(1.25)

Note. Table values represent means (and standard deviations). Scale: 0=none, 1= a little, 2=some, 3=quite a bit, 4=completely

Case managers' reports of services indicated that consumers in the new cohort were more likely to receive outpatient services (old cohort, 42%; new cohort, 56%), while individuals in the old cohort were more likely to receive community residential services (old cohort, 21%; new cohort, 11%), day services (old cohort, 29%; new cohort, 14%) and non office-based/outreach case management services (old cohort, 66%; new cohort, 52%). Perhaps the use of more "sheltered" services by individuals in the old cohort was appropriate given their age and higher rate of schizophrenia.

## Service empowerment

Individuals in the new cohort attributed more importance to being empowered with regard to their services and treatment. They were more likely to indicate that it was "quite a bit" or "extremely" important to have a say over the services they received (old cohort, 73%; new cohort, 86%) and be involved in medication decisions (old cohort, 71%; new cohort, 88%).

Likewise, individuals in the new cohort indicated that they were more involved and empowered with regard to service decisions. For example, they were more likely to report "quite a bit" or "complete" involvement in medication decisions (old cohort, 38%; new cohort, 54%), treatment planning (old cohort, 52%; new cohort, 67%) and resolving crises (old cohort, 56%; new cohort, 65%).

With regard to medication, individuals in the new cohort were more likely to indicate that someone had explained their medications to them (old cohort, 83%; new cohort, 95%) and described the side effects of their medications (old cohort, 71%; new cohort, 84%). However, they were also more likely to report that they did not adhere to their prescribed medication regimen (old cohort, 8%; new cohort, 17%).

According to consumers' self-reports and case managers' ratings, consumers in the new cohort experienced more supportive and empowering relationships with their case managers. For instance, consumers in the new cohort were more likely to indicate that their case managers "often" or "always" took their ideas and opinions into account (old cohort, 56%; new cohort, 78%). Thus, consumers in the new cohort were more empowered with regard to service decisions and their service relationships.

### **Relationships and social support**

Individuals in the new cohort reported less frequent contact with their friends compared to the longitudinal sample (weekly or daily contact: old cohort, 78%; new cohort, 45%). However, individuals in the new cohort reported that their relationships with their friends were more supportive and empowering. For instance, consumers in the new cohort were more likely to indicate that their friends "often" or "always" accepted them the way that they are (old cohort, 66%; new cohort, 79%).

### **Summary and implications for service providers**

Overall, the findings suggest that individuals who are currently entering 508 status are very different demographically and clinically than individuals who were 508 certified in the past. Compared to the longstanding 508 population, those currently entering the mental health system are more ethnically diverse, and have higher rates of depression, lower rates of schizophrenia and more physical healthcare needs.

There are a number of factors that may contribute to the observed changes in diagnostic characteristics. For instance, they may be related to changes in clinical practice and diagnosis or to practices related to the 508 certification process. However, they raise concern that fewer people with schizophrenia are being properly diagnosed and receiving the services that they need. The fact that individuals in the new cohort had more physical health problems, in spite of their younger age, suggests that physical health care services will be increasingly important for individuals entering the public mental health system.

The results also suggest that consumers who are currently entering the system are more empowered with regard to their services. In addition, they have more empowering and supportive relationships with their service providers. To some extent, these differences are in keeping with consumers' ratings of the importance of service empowerment. Consumers in the new cohort attributed more importance to being involved in decisions about their services. However, consumers in both the old and new cohorts reported that they wanted to be more involved than they currently were in service related decisions.

Though individuals in the new cohort are younger and more likely to indicate a desire to be employed, they are no more likely to work or volunteer than individuals in the old cohort. This finding may be related to the higher levels of physical disability

experienced by individuals in the new cohort. However, they suggest that vocational services continue to be unmet needs for mental health consumers.

LCO: DCR