

Report to Participants

Results of Ohio's Study of Longitudinal Consumer Outcomes 1995 – 1997/98

Carol Albritton Carstens, PhD, Technical Writer/Editor

Research supported by grants from the
National Institute of Mental Health and the
Ohio Department of Mental Health

Ohio Department of Mental Health Office of Program Evaluation and Research

The research team:

Dee Roth, MA
Michael Hannon, MA

Dushka Crane-Ross, PhD
Gary Cusick, PhD

December 1999

Introduction

The Longitudinal Consumer Outcomes study is part of a larger research project that has examined the experiences of public mental health consumers with severe mental disabilities since 1991. The original four-year project examined the relationship between mental health services received and what happened in consumers' lives. In addition to the project's original focus on community support and needs assessment, the current wave of measurement was designed to examine consumers' service empowerment, service relationships, perceptions of recovery, and criminal victimization and involvement. As part of that effort, hundreds of Ohioans graciously shared their time and experiences with our interviewers. The following information is based on data they provided in 1995 and 1997/98.

A Word of Thanks to Participants

Before we report our findings and conclusions, we would like to thank you for agreeing to be part of this research project. Your openness and willingness to share your views and experiences helped the research team and the Department examine the relationship between our public mental health system and the people it serves. We want you to know that because of what you told us, we were able to identify ways of improving the quality of services to mental health consumers in Ohio and make recommendations to policy makers, service providers, and administrators.

Longitudinal Consumer Outcomes

In the current the project we wanted to examine the experiences of consumers as the mental health system continued to undergo change. In addition to looking at the kinds of services individuals were receiving, we wanted to examine a broader range of issues, including service empowerment, service relationships, social support, and consumers' needs. By better understanding the consumers' perspectives on services, we hoped to better understand the links between:

- ◆ how people were doing in their day-to-day lives (consumer outcomes),
- ◆ the extent to which identified needs were being met (consumers' needs),
- ◆ where consumers were getting their needs met (from informal supports or service providers)
- ◆ the extent to which consumers were involved in decision making regarding the services they received (service empowerment)

Some interview questions were specifically designed to assess the extent to which consumers were involved in decisions about their housing, medication, services, and treatment. In addition, questions were included to assess the extent to which consumers felt supported and empowered in their relationships with service providers, family members, and friends. Participants' case managers responded to a questionnaire asking about participants' medications, diagnoses, symptoms, and functioning. Consumers' and case managers' ratings were compared to identify areas of agreement and areas of disagreement regarding unmet service needs.

People and Places

In the 1997/98 wave of data collection, 369 consumers participated in the Longitudinal Consumer Outcomes study. Of this group, 268 have participated in the study since 1991. The remaining 101 participants were consumers relatively new to the public mental health system. These were individuals who were 508 certified as having a severe mental disability for the first time in 1996. In the 1997/98 wave of data collection, we interviewed approximately 84 percent of 441 potential participants from four regional service areas of the state.

Potential respondents not interviewed were those who refused, were disabled or deceased. We were unable to locate some. About 60 percent of study participants were women, and some 23 percent of interviewees were minorities. The average age was 46, and most people were between the ages of 31 and 64. Approximately 30 percent of our respondents reported they had never married, 23 percent were currently married, and 30 percent said they were married at one time but were currently single.

The study's four regional sampling sites included places with poor as well as wealthier economies, industrial sites as well as farming areas. Approximately 25 percent of the participants were from the Montgomery County urban area, and another 25 percent came from the rural area of Adams, Lawrence and Scioto Counties. The rural Four-County area of Henry, Fulton, Defiance and Williams, contributed about 29 percent of the study's participants, while 21 percent were from the suburban area of Trumbull County.

The Results

1 The best predictor of positive mental health outcomes is the consumers' perception that their needs are being met.

When we analyzed what things were associated with fewer symptoms and a better quality of life, we saw that these outcomes are *not* related to amounts or types of services received but rather to people's opinions about whether or not their needs were being met.

"I need confidence in myself, and expressing my needs helps to increase confidence."

- ❖ It is important that you and your service providers work together to identify the services that fit your needs. We have recommended that service providers pay close attention to your views about what services are needed and the extent to which you think your needs are being met.

2 Vocational assistance and finding out about services are the top two unmet needs consumers identified in the survey.

We determined unmet needs by comparing the amount of help consumers said was needed in various areas of their lives with the amount of help they reported as received. Twelve areas of unmet needs were reported:

- ✓ Vocational assistance
- ✓ Finding out about available services
- ✓ Making friends
- ✓ Medical and dental care
- ✓ Educating others about problems
- ✓ Talking about problems
- ✓ Legal issues
- ✓ Benefits and income supports
- ✓ Complaining about services
- ✓ Interpersonal issues
- ✓ Housing
- ✓ Transportation

"I want to participate in a jobs program for handicapped people and make some friends."

- ❖ It is important that you and your service providers discuss your level of need in these areas. We have recommended that service providers focus particular attention in the areas of vocational assistance and providing information about the different types of services that are available to you.

- 3 Consumers have different perceptions than case managers about whether their needs are being met. It's important to remember that the consumers' perceptions of needs are a better predictor of a positive mental health status than case managers' perceptions of needs.** In contrast to the consumers' list of unmet needs, case managers thought consumers had only eight unmet needs:

- ✓ Making friends
- ✓ Vocational assistance
- ✓ Interpersonal issues
- ✓ Managing money
- ✓ Legal issues
- ✓ Managing medications
- ✓ Help with day-to-day things
- ✓ Medical and dental care

“Because I'm a client, I have say in my treatment programs. I'm knowledgeable in client's rights, so I use those to get what I think is right.”

Consumers reported that three of these needs were met or *overly met*, including managing money,

managing medications, and help with day-to-day things. However, service providers' views often did not reflect consumers' perceptions about what needs are important and unmet.

- ❖ It is important for your service providers to listen to your opinions about your needs and focus more on your views when developing treatment plans.

4 The level to which consumers feel involved in treatment planning and decisions about services is highly related to the degree to which they feel their needs are being met.

“I've been off medication for awhile, but they leave it up to me. If I wanted to see my case manager I could. I tell them what the problem is, and they take care of it.”

the degree to which they feel their needs are being met.

Consumers who reported feeling more empowered about

mental health services seem to be better able to get their needs met, and getting needs met has the greatest impact on positive mental health outcomes.

- ❖ **It is important for you to feel that your opinions are valued and respected by your service providers.**

5 In the area of mental health services and treatment, consumers do not perceive themselves to be as empowered as they would like to be.

Less than half of the consumers we interviewed reported feeling “quite a bit” or “extremely” involved in decisions regarding services and treatment or medications. Nevertheless, the majority of consumers indicated that it was “quite a bit” or “extremely” important to have some say about services and be involved in decisions regarding medications. The majority of consumers also reported feeling responsible for carrying out the goals of their treatment plans.

“If I feel something is not right I can go to my therapist or my case manager and they will investigate. They are really important in my life the last four years. If they are not in, I leave a message and they immediately get back to me.”

- ❖ For services to be effective, you must be able to play a meaningful part in decisions about your treatment.

6 Employment is a leading unmet need, and the gap between the employed and unemployed is huge. Only 25% of consumers reported working or volunteering, and an even smaller group--16%--reported receiving income from working. However, 59% indicated that it was “moderately” to “extremely” important to work.

- ❖ It is evident that more vocational assistance and more innovative job programs are needed.

7 Consumers’ compliance with medication regimens depends on their level of involvement in decisions about medications and whether or not they receive information about prescriptions and possible side effects.

Consumers who reported involvement in medication decisions are more likely to take medication as prescribed and to need less help managing medications. Similarly, consumers who were given an explanation of medications and side effects were less likely to need assistance with medication management.

“My wife, the case manager, and the doctor worked with me to get me on the right medicine. When I had a problem, they'd sit down with me and listen and not shame me inside. That meant a lot.”

- ❖ We feel it is important for service providers to give you as much information as possible about medications and side effects so that you can be actively involved in decisions about your treatment. It is also important for doctors to closely monitor your medication levels and pay attention to side effects.

8 Consumers we interviewed told us that a variety of interventions help their progress toward recovery.

Following is a list of things that consumers reported as most important to people’s recovery:

Intervention	Percent of All Responses
Medication	31%
Self-initiated activities	26%
Family support	22%
Medical personnel	15%
Friend support	14%
Agency services/staff	14%
Spirituality	14%
Talking to someone	11%
Case managers	9%
Counselors and therapists	8%

“I’ve learned to choose wisely what I do, accept limitations and work around them. Doing crafts keeps my mind off my problems.”

- ❖ These are important areas to address and incorporate into treatment plans.

9 Reports of crime victimization are high for all participants in the study, particularly for those who are relatively new to the mental health system. Among those who entered the public mental health system prior to 1991, 34 percent reported a physical assault and 24 percent reported a sexual assault at some point during their lives. For those who are relatively new to the mental health system, the rates of victimization are higher: 46 percent reported a physical assault and 30 percent reported a sexual assault at some time during their lives.

- ❖ It is important that you receive information or assistance to help you stay safe.

Our analysis of the answers provided by consumers produced many findings not reported here. For a more detailed discussion of results, please visit our web page at:

<http://www.mh.state.oh.us/oper/oper.index.html>