Toward Best Practices:

Top Ten Findings from the Longitudinal Consumer Outcomes Study 1999



Ohio Department of Mental Health
Office of Program Evaluation & Research

Ohio Department of Mental Health Office of the Director 30 E. Broad Street, 8th Floor Columbus, Ohio 43266-0414

October 27, 1999

Dear Colleagues:

In the past several decades, Ohio has dramatically transformed its public mental health system, moving from a state oriented and institutionally based model to locally managed community support. This accomplishment has now focused our attention on the quality of services, and on consumers' progress toward recovery.

During this period, a ground-breaking study conducted by ODMH has revealed new patterns, problems and potentials in community care. We have summarized the "Top Ten" findings from this research, in the hope that the research will assist in local progress toward quality and recovery.

Best wishes,

Michael F. Hogan, Ph.D. Director

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Dear Colleagues:

All of the findings in this booklet have come from the most recent round of data collection in our longitudinal study of consumers and services in the Ohio community mental health system. You will find a short description of the research on the next page.

We are very aware that it is difficult for busy service providers and administrators to find the time to read long research reports, so we developed this very short format to give readers a sense of the major findings of the study. These finding have very important implications for policy and practice and for improving services and outcomes for consumers, and we hope that you will be interested in reading more. At the end of the booklet you will find a list of publications that will give you more information about the methodology of the study and the wide range of results that we have found. If you do not have these documents, please get in touch with us and we will send them to you.

We hope that you will be able to use a number of these findings to improve practices and outcomes for consumers served in your local mental health system. We would very much like to talk with you about your questions or hear about your experiences in using the reseach results. We encourage you to get in touch with us for further discussion.

Sincerely,

Dee Roth, M.A. Chief

LCO Study Background

The LCO study is part of a longitudinal study of the mental health services, needs, and outcomes of adult consumers with severe mental disabilities (SMD) in Ohio. This research includes five waves of measurement, spanning a period of eight years (1991 – 1998). At each wave, consumers have participated in in-depth interviews regarding their services, needs, and outcomes. Their case managers have provided additional information about needs, clinical diagnoses, medications, symptomatology and functioning. The study was conducted in two urban and two rural board areas in Ohio. The original sample included 457 consumers. At the fifth wave of measurement the sample included 268 of the original participants. In addition, a new cohort of 101 consumers was included to examine needs and other characteristics of consumers currently entering the mental health system.

This study was originally designed to test a model that included client and service system characteristics, service mix received, and consumer outcomes achieved. Over time, the study has been adapted to incorporate new issues relevant to mental health consumers. For example, questions were added to the consumer and case manager surveys to examine issues such as service empowerment, recovery, effects of using new antipsychotic medications, and crime victimization and perpetration.

Consumers' perceptions that their needs are met are the best predictors of positive mental health outcomes. In the most recent measurement period of the study, structural equation modeling was used to identify those things most highly linked to consumer outcomes. The consumer's perception of the degree to which his/her needs were being met was the strongest predictor and accounted for 20 percent of the variance in symptomatology outcomes and 35 percent of the variance in quality of life outcomes. Mental health outcomes were not related to the amounts or types of services consumers received.

<u>Practice implication</u>: In order to improve consumers' outcomes, service providers must attend to individual consumers' perceptions of what services are needed and the extent to which consumers think their needs are being met. Additionally, the fact that there is not a link between service use and outcomes suggests that services—while perhaps caring and competent at "keeping people out of hospitals"—are not as focused as needed. Given the strong evidence that certain well-structured services are effective (e.g., PACT, family/consumer education and support groups), there is also a need to incorporate proven practices into Ohio CSP programs.

McFarlane, W. R. (1997). Family psychoeducation: Basic concepts and innovative applications. In S. W. Henggeler & W. Scott (Eds.), <u>Innovative approaches for difficult-to-treat populations</u>. Washinton, DC: American Psychiatric Press.

Stein, L. I., Barry, K. L., Van Dien, G., Hollingsworth, E. J., & Sweeney, J. K. (1999). Work and social support: A comparison of consumers who have achieved stability in ACT and clubhouse programs. Community Mental Health Journal, 35(2), 193-204.

Stein, L. I., & Santos, A. B. (1998). Assertive community treatment of persons with severe mental illness. NY: Norton.

- The top two unmet needs identified by consumers are (1) vocational assistance, and (2) finding out about services. By comparing the amount of help consumers need in a number of areas with the amount of help they receive, the LCO study was able to determine unmet need. According to consumers, 12 needs were unmet:
 - 1. Vocational assistance
 - 2. Finding out about available services
 - 3. Making friends
 - 4. Medical and dental care
 - 5. Educating others about their problems
 - 6. Talking about problems
 - 7. Legal issues
 - 8. Benefits and income supports
 - 9. Complaining about services
 - 10. Interpersonal issues
 - 11. Housing
 - 12. Transportation

The top two unmet needs identified by consumers have remained the same in every year of the LCO study.

<u>Practice implication</u>: Local systems need to concentrate more energy on meeting consumers' needs, especially in the areas of vocational assistance and information about available services.

- Consumers and case managers have different perceptions of met needs. Consumers' perceptions of needs are better predictors of mental health outcomes than are case managers' perceptions of needs. In contrast to the previous list, case managers thought that consumers had only eight unmet needs:
 - 1. Making friends
 - 2. Vocational assistance
 - 3. Interpersonal issues
 - 4. Managing money
 - 5. Legal issues
 - 6. Managing medications
 - 7. Help with day-to-day things
 - 8. Medical and dental care

Three of these needs were actually seen as met or overly met by consumers, including interpersonal issues, managing money and managing medications. In contrast to the percentages described in Finding #1, case mangers' perceptions of met needs predicted less than one percent of the variance in symptomatology and quality of life outcomes and 14 percent of the variance in functioning outcomes.

<u>Practice implications</u>: Service providers' views often do not reflect consumers' perceptions of their needs. Providers should re-examine how or the extent to which they engage in active listening to consumers around their needs and work toward incorporating more of the consumer's perspective in treatment planning.

Consumers' perceptions of their level of service empowerment (e.g., their involvement in treatment planning and decisions about services) was the variable most highly correlated with the degree to which they felt their needs were being met. Empowerment accounted for approximately 21 percent of the variance in met needs. Consumers who feel more empowered seem to be more able to get their needs met. As indicated in Finding #1, getting needs met has the greatest impact on positive outcomes.

<u>Practice implication</u>: It is critical that consumers feel a genuine sense of empowerment in their relationships with service providers.

Consumers do not perceive themselves to be as empowered as they would like to be, with regard to their services and treatment. Less than half of consumers reported that they were quite a bit or extremely involved in decisions regarding their services and treatment (47%) or their medications (43%). In contrast, the majority indicated that it was quite a bit or extremely important to have some say over their services (77%) and be involved in medication decisions (76%). On the other hand, the majority of consumers (70%) felt responsible for carrying out their treatment plan goals.

<u>Practice implication</u>: In order for services to be effective, consumers need to play a meaningful part in decisions about their treatment.

Consumers who are newer to the system have different characteristics and needs. Compared to consumers who were 508 certified in the past, consumers who are currently entering 508 status have higher rates of mood disorder, lower rates of schizophrenia, lower quality of life and more physical health problems.

Mood disorder was the primary diagnosis among LCO participants who were newly certified in 1996. In contrast, schizophrenia and other psychoses were the most frequent primary diagnoses among individuals who were 508 certified prior to 1991. Newly certified participants also reported a lower quality of life with regard to their life as a whole, and in relation to specific areas including physical health, leisure activities, and finances. Ages were approximately equivalent for both groups at their initial entry into the study.

<u>Practice and policy questions</u>: Are consumers with schizophrenia being identified and receiving the services that they need? Are service providers responding to the different diagnostic profiles and the greater need for physical health care among newly certified consumers?

The "employment gap" for consumers is still huge. Only 26% of consumers reported working or volunteering; 16% reported the they received income from working. However, 59% of consumers indicated that it was moderately to extremely important to work, and employment was a leading unmet need identified by both consumers and case managers. Individuals recently 508 certified were no more likely than those 508 certified in the past to work or volunteer, though they were younger and attribute more importance to being employed.

<u>Practice and policy implication</u>: More emphasis on employment is needed for the severely mentally disabled adult population. Given the strong evidence in favor of specific supported employment practices, these approaches should be implemented in Ohio.

Bond, G.R. (1998). Principles of the individual placement and support model: Empirical support. <u>Psychiatric Rehabilitation Journal.</u> 22(1), 11-23.

Hogan, M. (1999). How can mental health leaders make a difference? <u>A Technical Assistance Tool Kit on Employment for People with Psychiatric Disabilities</u>. Alexandria VA: National Association of State Mental Health Program Directors.

Consumers' adherence to medication regimens depends on their level of involvement in decisions regarding their medications, and whether they receive information about their medications and side effects. Those consumers who were involved in medication decisions were more likely to take their medication as prescribed and needed less assistance managing their medications. Similarly, consumers who had their medications and side effects explained to them needed less assistance with medication management. Early results suggest that the use of new, atypical antipsychotic medications does not increase medication adherence.

<u>Practice implication</u>: Frequent communication between consumers and medical staff regarding their medications and side effects is essential to increasing medication adherence. As described in finding #5, consumers perceive themselves to be less involved than they wish to be in medication related decisions.

9 Consumers indicated that a variety of things help their progress toward recovery:

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%

Practice question: Are treatment plans addressing and incorporating these important areas?

10 Crime victimization is high among all consumers, but even higher among individuals who are relatively new to the mental health system. Thirty four percent of the old cohort and 46 percent of the new cohort reported being victims of a physical assault at some point during their lives. Twenty-four percent of the old cohort and 30 percent of the new cohort reported being pressured or forced into sexual activity at some point during their lives.

<u>Practice question</u>: Are treatment plans including education and interventions to help people stay safe?

More information about the SIS/LCO study is available in the following sources:

Roth, D., Crane-Ross, D., Hannon, M., & Cusick, G. (in preparation). A longitudinal study of mental health services and consumer outcomes in a changing system. In D. Roth (Ed.), New Research in Mental Health, Vol. 14. Columbus, OH: Ohio Department of Mental Health.

Crane-Ross, D., & Roth, D. (in press). Consumers' and case managers' perceptions of mental health and community support service needs. Community Mental Health Journal.

Crane-Ross, D., & Lutz, W. (December, 1999). <u>Evaluating a medication management model for consumers in a public mental health system.</u> Paper presented at the Sixth Annual Florida Conference on Behavioral Healthcare Evaluation, Orlando, FL.

Roth, D., Crane-Ross, D., Hannon, M., Cusick, G., & Doklovic, S. (1998). Longitudinal study of mental health services and consumer outcomes in a changing system. In D. Roth (Ed.), New Research in Mental Health, Vol. 13 (pp. 104 – 116). Columbus, OH: Ohio Department of Mental Health.

Roth, D., Snapp, M. B., Lauber, B. G., & Clark, J. A. (1998). Consumer turnover in identified patterns of community mental health service utilization. Administration and Policy in Mental Health, 25 (3), 241-255.

Roth, D., Lauber, B. G., Crane-Ross, D. A., & Clark, J. A. (1997). Impact of state mental health reform on patterns of service delivery. Community Mental Health Journal, 3, 473-486.

Roth, D., Crane-Ross, D., Doklovic, S., Vercellini, J., Burns, G., Frazier, M., & Lauber, B. (1996). A longitudinal study of mental health services and consumer outcomes in a changing system. In D. Roth (Ed.), New Research in Mental Health, Vol. 12 (pp. 184 - 197). Columbus, OH: Ohio Department of Mental Health.

Roth, D., Lauber, B. G., Vercellini, J., Burns, G., Champney, T. F., & Clark, J. (1996). Services in systems: Impact on client outcomes. In D. Roth (Ed.), New Research in Mental Health, Vol. 12 (pp. 388 - 401). Columbus, OH: Ohio Department of Mental Health.

Roth, D., Lauber, B. G., Clark, J. A., Vercellini, J., Frazier, M., & Hogan, M. F. (1995). Final results: Ohio's study of services, systems and outcomes in an era of change. Proceedings of the Fifth Annual Conference on State Mental Health Agency Services Research (pp. 85-103). Alexandria, VA: The National Association of State Mental Health Program Directors Research Institute, Inc.

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