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## Measuring System Impacts on Mental Health Recovery: First Results from a National Research Project

**W**hat is mental health recovery? What helps the individual in the process of recovery? What hinders? How do mental health systems and staff help, and how do they hinder? How can these effects be measured? A recent report entitled "Mental Health Recovery: What Helps and What Hinders?"<sup>1</sup> represents the first step of a national project designed to address these questions.

### The Recovery Report

The report presents findings from the project's first phase, a qualitative study of consumers' experiences of what has helped and hindered in their recovery—including, but not limited to, characteristics of the mental health service system. This study consisted of structured focus groups with a diverse cross section of consumer/survivors as participants. The results from the focus groups will provide the empirical foundation for the project's next phase of developing and testing measures

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## The Evaluation Center@HSRI

is a technical assistance center funded by the federal Center for Mental Health Services (CMHS), Substance Abuse and Mental Health Services Administration (SAMHSA), and operated by the Human Services Research Institute (HSRI). The mission of the Center is to provide evaluation technical assistance to state and non-profit and private entities including, but not limited to, consumers, families and provider groups. The Center presently has six programs designed to fulfill this mission—

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of how state and local mental health systems perform in promoting recovery. These measures will be used in “report cards” to compare mental health systems on the basis of what they do to help or hinder consumers in the recovery process. A subset of the measures will be incorporated into the Mental Health Statistics Improvement Program (MHSIP) Consumer-oriented Report Card Version 2, scheduled for release in the spring of 2003.

In addition to the function of providing data for measure development, the report stands on its own in several respects. First, it explores the many nuances and complexities of recovery, illustrating these by quoting extensively from the study participants. The result is a profound and compelling narrative of the recovery experience, told in the many voices of a diverse cross-section of consumer/survivors. More concretely, it offers to anyone engaged in the formal mental health system—line staff, administrator, policy maker or consumer—a wealth of knowledge about what is necessary for mental health services to be truly responsive to the needs of persons with psychiatric disabilities.

### **Background of the Recovery Project**

The term “recovery”, in the context of mental health, signifies the recognition that “people can successfully contend with severe and persistent psychiatric disorder, function well, and create positive lives” (Onken, Dumont et al. 2002, p. 1). Definitions of recovery generally identify both internal (self) and external (environmental/social) factors, and the dynamic interplay between them. Hope, empowerment, self-management and social relationships are prominent themes. As such, the concept of recovery embraces the complex set of experiences and beliefs that have shaped the mental health consumer/survivor movement from its origins in the early 1970’s

(Onken, Dumont et al. 2002, p. 7).

As the concept of mental health recovery gained recognition, consumers and researchers (including consumer-researchers) began to explore ways to measure an individual’s progress in recovery as an outcome (Ralph, Kidder et al. 2000). “Mental Health Recovery: What Helps and What Hinders?” represents the next step, of measuring the degree to which mental health systems, services and staff positively and negatively affect the individual’s progress.

The Recovery Project originated in the Mental Health Statistics Improvement Program (MHSIP) 16-State Indicator Project, a collaboration by several participating states that had been independently exploring the idea of recovery-related systems performance measures

(<http://www.mhsip.org/sixteenstate/index.htm>). Mental health planners and administrators from these states formed a workgroup, to which they added consumers and researchers experienced and knowledgeable in the recovery field. In May 2000 this “expert panel” met in Austin Texas to develop a working definition of recovery and on the basis of this, to identify key domains of recovery and some items that might be used to assess these domains.

### **The National Study**

At this point, the group recognized a need for additional knowledge about consumers’ perceptions of what helps and hinders recovery, beyond that available from the literature and the expertise available within the group. Accordingly they formed a research team from the workgroup membership and launched the national study of consumer perspectives. The team consists of Steven J. Onken, Ph.D. and Jeanne M. Dumont Ph.D. as Co-Principal In-

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investigators and Priscilla Ridgway, M.S.W., A.B.D., Douglas H. Dornan, M.S., and Ruth O. Ralph, Ph.D. as Co-Investigators, all of whom are national leaders in the field of recovery research. A group of federal, academic and private organizations<sup>2</sup> are sponsoring the project and nine state mental health authorities (SMHAs)<sup>3</sup> are collaborating in carrying it out.

### **Design of the Consumer Perspectives Study**

For this phase of the project, the nine SMHA's recruited a total of 115 consumer/survivors to participate in 10 structured focus groups. The SMHAs employed a purposive sampling strategy to attain a cross-section of consumer/survivors representing diverse geographical settings (urban, rural and suburban), patterns of service utilization, demographic characteristics, stages of recovery, and involvement in the consumer/survivor movement.

Group leaders presented participants with standardized, open-ended "question sets" about what helped and hindered in five hypothesized domains of recovery that had been identified by the expert panel. One domain, for example, was "resources/basic needs," and the questions were "What resources are important for you to have control of your life?", "What helps you get these resources" and "What gets in the way of getting these resources?" Similar questions addressed the other four domains: choices/self-determination; independence/ Sovereignty; interdependence/connectiveness; and hope.

To capture the entire range of factors that help and hinder recovery in each of these domains, questions about the service system specifically were held until the last. These were "How have mental health staff and mental health services helped or hindered you in your life with gaining resources, choices, independence, connections with others, and hope?"

and "If you were giving advice to mental health decision makers in your state, what things would you tell them that they or staff could do to make your life better." Using qualitative research methods, the research team then analyzed the complete transcriptions of the focus group responses to the seven question sets.

### **Findings of the Consumer Perspectives Study**

Systematic analysis of the focus group transcriptions produced a set of ten "recovery themes" that revise and expand upon the expert panel's five domains:

- resources/basic needs choices/self-determination
- independence/ sovereignty
- social relationships/connectiveness
- hope/meaning/purpose
- self/whole person
- meaningful activities
- peer support
- formal services
- formal service staff.

Each of the themes incorporates a set of five to ten factors that help and hinder recovery. For the service system theme, helping and hindering factors are broken down further into categories of "organizational culture and structure" and "programs and services."

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Space does not permit listing all the helping and hindering factors that constitute the recovery themes. In general these are divided into characteristics of the individual (self) and of the environment (mental health system, society) and reflect a balance between autonomy, responsibility and freedom of choice on the one hand, and on the other, respect, support and opportunities, both material and psychological. Examples of what hinders in the formal services theme are “treatment/medication used as a means of social control” and “lack of education for consumers, family members and community.” Corresponding helping factors are “freedom of whether and how to participate in services and medication / self-management of medication” and “patient education/illness education/information on medications, effective treatments and services and how to secure, rights/family education/public awareness education (anti-stigma and pro-recovery).”

The authors observe that the recovery themes constitute an emergent paradigm for understanding the phenomenon of mental health recovery. This paradigm represents recovery as a personal process reflecting a dynamic interaction between the individual, the environment, and the exchange between them. Recovery is strongly affected by, but also extends beyond, the formal service system. The authors note as well that many of the things identified as critical to recovery are consistent with what most Americans value: safety, adequate income, a secure job, decent home, friends, family, intimacy, and community involvement. The full report is available at the following Website <http://www.nasmhpd.org/ntac/reports/index.html> in PDF format under the October 2002 listing.

The project team is now at work formulating sys-

tem-level measures that will use both administrative and consumer level information. These will be field tested over the coming months, with the final product expected by Spring, 2003.

## REFERENCES

- Onken, S.J., Dumont, J.M., Ridgway, P., Dornan, D.H., & Ralph, R.O. (2002). *Mental Health Recovery: What Helps and What Hinders?* Alexandria, VA, National Technical Assistance Center for State Mental Health Planning.
- Ralph, R., K. Kidder, et al. (2000). *Can we measure recovery? A compendium of recovery and recovery-related instruments.* Cambridge, MA, The Evaluation Center@HSRI.

## END NOTES:

- 1 Available at <http://www.nasmhpd.org/ntac/reports/index.html>
- 2 Center for Mental Health Services (CMHS) Survey and Analysis Branch, Columbia University Center for the Study of Social Work Practice, Human Services Research Institute (HSRI), Missouri Institute of Mental Health (MIMH), NASMHPD Research Institute (NRI), Nathan Kline Institute for Psychiatric Research, Center for the Study of Issues in Public Mental Health (CSIPMH), National Association of State Mental Health Program Directors (NASMHPD) National Technical Assistance Center (NTAC), New York State Office of Mental Health, Oklahoma Department of Mental Health and Substance Abuse Services
- 3 Arizona, Colorado, New York, Oklahoma, Rhode Island, Texas, Utah and Washington.

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