

Tools In Development: Measuring Recovery at the Individual, Program, and System Levels

For many SMHA administrators, offering reimbursable programs and services is the only way to maintain a viable mental health organization. This scenario is not always conducive to implementing new methods and services, many of which are not yet considered evidence-based practices. Recovery should be measurable, though, because for SMHAs it's an accountability issue, and there are quantitative and qualitative aspects to it at the individual, program, and system levels. Today's SMHAs need concrete, replicable, measurable services, and therefore many state mental health officials are looking for tools to help quantify recovery-based care.

Despite the reality that research on recovery measurement is in a relatively fledgling state, there are a variety of recovery-themed measurement tools in various stages of development that are being created to help administrators, clinicians, peer providers, and consumers institute recovery-based care into mental health settings. This special report features a sampling of three separate recovery measurement tools—all in development—including descriptions and progress updates written by representatives of the three efforts.

Ruth Ralph, Ph.D., offers a report on the effort to create a personal measure of recovery within the Recovery Measurement Tool and the Recovery Model. Priscilla Ridgway provides an update on the Recovery Enhancing Environment Measure, which is intended to assess the recovery orientation of mental health programs, and Steve Onken, Ph.D. offers a look at a system-wide tool, the Recovery Oriented System Indicators (ROSI) Measure.

Editor's note: This is not an exclusive list of measures, as there are other measures for recovery in use and/or in development across the country. NASMHPD/NTAC does not necessarily endorse the aforementioned three measures over any others.

At the Individual Level: A Personal Measure of Recovery

By Ruth O. Ralph, Ph.D.

Dr. Ralph, a retired senior research associate with the Edmund S. Muskie School of Public Service at the University of Southern Maine, is a consumer researcher who has conducted mental health research and evaluation for over 25 years.

The Recovery Measurement Tool (RMT) is based upon The Recovery Advisory Group Recovery Model (Ralph & The Recovery Advisory Group, 1999). It is important to review this model in order to understand the background of the RMT.

When the Recovery Advisory Group¹ was formed in 1999, monthly teleconferences were held to discuss recovery issues. The discussions were based on the considerable experience of the group's members and exchange and discourse of readings about recovery, both published and unpublished. It was the hope of the group's CMHS funders that these discussions would lead to measurement of recovery.

However, the group focused on definition(s) of recovery, and realized that there needed to be a visual way of portraying recovery. Thus, The Recovery Model was developed, discussed, and revised until members of the group felt it truly portrayed a viable description of recovery.

There are several parts to the model [all parts of the Recovery Model are available on the Web at http://www.nasmhpd.org/spec_e-report_fall04measures.cfm]. The first shows a series of ovals to portray the stages one goes through on the way to recovery. These are shown as: anguish, awakening, insight, action plan, determination to be well, and well-being/recovery. The progress through these stages is not linear, but involves considerable moving back and forth, from one stage to another, and possibly backward when things aren't going well. The ovals are arranged in a beginning spiral, to show that one can move through the spiral, and possibly start again, but maybe on a higher plane.

The second part of the model is a grid that shows these stages across the top, with internal and external domains down the left side. In the model, each "box" has a statement that describes recovery at that point in the journey. This grid became an important component in the development of the Recovery Measurement Tool. The third part of the model shows both negative and positive external influences on a person who is working on recovery. The fourth part summarizes the model by placing the person who is going through the stages in the center (represented by a circle) surrounded by both negative and positive external influences. This part is called "The Big Picture."

The development of The Recovery Measurement Tool (RMT) was funded by the Center for the Study of Public Issues in Mental Health located in New York State. A group of consumers from Maine met and reviewed the Recovery Model, with special attention given to the grid with the descriptive statements about the stages of recovery. Using the grid, we developed one or more items for each of the intersecting boxes in the grid. For example, the item "There is hope for me even when I do not feel well," is in the Insight/Emotional box. The item "I visit a number of places to see where I can make friends," is in the Determined Commitment/Activities box.

The result, over a number of meetings, was the development of 100 items. While we worked on this project, we read and discussed information about how to write items—how they should have only one idea, and how they should be clearly written so that they could be understood easily.

¹ The Recovery Advisory Group consisted of the following consumer leaders: Jean Campbell, Ph.D., Sylvia Caras, Ph.D., Jeanne Dumont, Ph.D., Dan Fisher, M.D., Ph.D., J.Rock Johnson, J.D., Carrie Kaufmann, Ph.D., Kathryn Kidder, M.A., Ed Knight, Ph.D., Ann Loder, Darby Penny, Ruth Ralph, Ph.D., Jean Risman, Wilma Townsend, and Laura Van Tosh.

We also learned about research issues, and how to “test a test.” We came together as strangers, but through this learning experience we bonded as co-workers and friends. We found that while we came from different backgrounds and had different experiences, “our feelings were the same, and we learned about ways to express them in order that others might also be able to express theirs” (Kidder, 2001).

In selecting a response set for these items, we reviewed a number of different types. However, because we wanted this to be a personal measure of recovery, we decided to make the responses range from “not at all like me,” through “not very much like me,” and “somewhat like me” to “quite a bit like me” and “very much like me.” We also included a column of “not applicable.” A thorough review of the items revealed nine items that were duplicates or near duplicates of other items, so they were deleted. The result is a total of 91 items.

Items were randomly arranged with the response format placed at the right of each item. Some information about demographics, e.g., age, sex, education, race/ethnicity, and location were added. This instrument has not been tested with any group at this time. It is hoped that this can be done soon, and a shorter, valid instrument can be constructed from the results.

References

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At the Program Level: The Recovery Enhancing Environment Measure

By Priscilla Ridgway, M.S.W.

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Introduction and Purpose of the Measure

Increasing importance is being placed on moving mental health systems toward a recovery orientation. The need to shift the driving focus of service delivery is evident in strong recommendations made by the Surgeon General (US DHHS, 1999) and the President’s New

Freedom Commission on Mental Health (2003). Given the call for such profound change, mental health administrators across the country are asking questions such as: What services and supports are important in a recovery-oriented mental health system? What recovery-facilitating practices are currently underdeveloped in our system? Where are the people we serve on their journey of recovery? How well are we facilitating people's potential for resilience and recovery? The Recovery Enhancing Environment measure (REE) was designed to provide empirical answers to such pressing concerns.

Developing and Testing the REE Measure

REE was created in 1999. The content of the measure was developed based on: 1) an examination of first person accounts of the process of mental health recovery and the services and supports people say enhance their recovery; 2) a review of emerging promising practices that promote recovery drawn from informal literature, workshop descriptions, and progressive programs; and, 3) a literature review of factors that facilitate resilience, or that help people rebound from adversity, in general.

The REE measure was reviewed and pre-tested by Kansans involved in a Consumer-as-Provider training program, and later by persons served by a day treatment program. Items were revised, dropped, and added based on consumer input. The measure underwent technical edits and the format was refined based on the input of colleagues Allan Press and Patricia E. Deegan.

Two formal pilot tests were conducted on the REE. In 2002, the Kansas Department of Social and Rehabilitation Services funded a mail survey of those served in the seven largest community support programs in the state. It was conducted by the Kansas University Office of Mental Health Research and Training in collaboration with participating community mental health centers (Ridgway, Press, Ratzlaff, Davidson, & Rapp, 2003). More recently, Pat Deegan & Associates trained a cadre of mental health consumers to gather REE data in face-to-face interviews with nearly half of those served by a large Massachusetts mental health agency (Ridgway, Press, Anderson, & Deegan, in preparation). More than 500 people completed the REE in the two pilots. Preliminary statistical analyses indicate that the instrument is psychometrically sound.

Content of the Measure

The REE instrument examines personal recovery by looking at the respondent's self-perceived stage of recovery and the markers of recovery (intermediate outcomes) they currently experience. Respondents rate the degree to which 24 elements are important to their personal recovery to increase our understanding of the process, using a 5 point scale ranging from "strongly agree" to "strongly disagree." These elements include hope, being able to manage symptoms, overall health and wellness, having one's rights respected, being involved in and a part of the larger community, having meaningful activities, taking on normal social roles, having positive relationships, identifying and building on personal strengths, having one's basic needs met, self-help and peer support, and others.

In order to assess the recovery orientation of the agency, people rate the current status of three specific staff behaviors or services that support each recovery element. Consumer perceptions are also gathered on the importance and existence of qualities of the service environment that have been found to enhance the potential for resilience. These include the presence of caring and compassionate helpers; opportunities for meaningful participation and contribution; being connected to others in positive ways; and feeling valued, respected, and powerful, among others. The degree to which the agency meets the perceived needs of people on dual journeys of recovery (those who experience dual diagnoses, trauma survivors), those from minority cultural backgrounds and sexual orientations, and recipients who are parents is also examined.

Findings

The findings of the pilots show that mental health recovery is a multi-dimensional process. People are able to place themselves within a particular stage of recovery. Most people are in an active phase of recovery, but many are not yet in recovery, a few experience setbacks, and some view themselves as fully recovered, but having to maintain their gains. Many respondents have one or more special needs. Almost all people can identify at least a few indicators of recovery in their lives, and many are able to claim several markers of personal recovery. These markers include being involved in productive activities, having trusted people to turn to for help, having goals one is working to achieve, controlling important decisions, feeling hopeful about the future, having one's symptoms under control, working, having a sense of belonging, and several others. These markers have performed well as a measure of change over time in other research. People gain ground concurrent with, or in part due to, exposure to recovery-enhancing programming.

REE begins to define a complex set of activities that enhance the potential for recovery from the perspective of service recipients. Consumers were able to differentiate higher performing programs from lower performing programs on the basis of statistically significant differences in the mean rating of program performance, as well as significant differences within and among programs along specific dimensions of practice.

Listening to the Voice of Lived Experience

The REE includes open-ended questions that ask people about the lessons they have learned in their own recovery and that give advice to staff and to others just starting out on a journey of recovery. These data were analyzed by themes. A few quotes give the flavor of the wisdom people generously shared.

“Never give up on you. Keep your head up. Everyone else might give up, but don't give up on you, because if you do, there is nothing else to live for. Do the best you can do every day. Never quit. Don't say I can't. Can't never did anything.”

“Don't go it alone. We are survivors, and although the trip is hard, it is well worth the wealth of knowledge, understanding and the happiness you will be

able to regain.”

“You will need a philosophy. I have one for you. It is four words, all action verbs: work, play, rest, love (what you can).”

Discussion

The REE allows programs to gather data from the recipients of services to assess gaps in important dimensions of recovery-enhancing programming, and to understand the needs of those who have not yet begun to recover or to experience recovery outcomes. In the spirit of appreciative inquiry, REE data can also be used to identify and celebrate positive elements of the program that are already in place that support people in their recovery, and the progress and wisdom of participants who are already moving forward in recovery.

Data from the REE can be used to plan recovery interventions, retrain staff, and target program innovations. The measure is intended to serve as a useful tool in processes of strategic planning that involve consumers, staff and administrators in point-in-time or on-going agency self-assessment or program evaluation efforts.

REE requires a significant investment of time and resources, but these are well spent if the data are used to identify priorities for program development and to set specific targets for transforming mental health agencies, thereby enhancing the potential for recovery among people using mental health services. REE is one of several tools that can help the field move toward fulfilling the vision that all mental health systems assume a recovery orientation, and that recovery is possible for everyone.

The REE measure is complete and in a scantrons (computer read) format. Permission to use the measure and ordering information are available from PRidgway@ku.edu. A brief user's guide, an MS Word version of the measure, a booklet summarizing the wisdom of people in recovery, and reports on the pilots should be available as of September 2004, from the Office of Mental Health Research and Training, University of Kansas, School of Social Welfare, Lawrence KS, 66045.

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At the System Level:

Consumer Self-Report Survey and Administrative-Data Profile

By Steven J. Onken, Ph.D., representing his fellow researcher team members Jeanne M. Dumont, Ph.D., Priscilla Ridgway, M.S.W., Douglas H. Dornan, M.S., and Ruth O. Ralph, Ph.D.

Dr. Onken is an assistant professor at the Columbia University School of Social Work and a co-principal investigator of the Mental Health Recovery: What Helps and What Hinders? National Research Project.

The Recovery Oriented System Indicators (ROSI) Measure is the product of the *Mental Health Recovery: What Helps and What Hinders? A National Research Project for the Development of Recovery Facilitating System Performance Indicators* effort. This research project evolved from collaborative efforts among a team of consumer and non-consumer researchers, state mental health authorities² (SMHAs), and a consortium of sponsors³ working to operationalize a set of mental health system performance indicators for mental health recovery.

Conceptualized and directed by a five-member research team (the majority of whom are primary consumers) as a three-phase process (i.e. grounded theory inquiry concerning the phenomenon of recovery; creation of prototype systems-level performance indicators; and large-scale pilot testing), Phase One and Two have been completed. This briefing summarizes the research process and resulting ROSI measure.

² AZ Dept of Health Services Div of Behavioral Health Services, CO Mental Health Services, NY State Office of Mental Health, OK Dept of Mental Health & Substance Abuse Services, RI Dept of Mental Health/Mental Retardation, SC Dept of Mental Health, TX Dept of Mental Health & Mental Retardation, University of HI-Manoa Adult Mental Health Div, UT Div of Mental Health, WA Dept of Social & Health Services Mental Health Div.

³ Center for Mental Health Services, CO Mental Health Services, Columbia University Center for the Study of Social Work Practice, Human Services Research Institute, Mental Health Empowerment Project, MO Institute of Mental Health, Nathan Kline Institute Center for Study of Issues in Public Mental Health, National Association of State Mental Health Program Directors, National Technical Assistance Center for State Mental Health Planning, & NASMHPD Research Institute, Inc., NY State Office of Mental Health, OK Dept of Mental Health and Substance Abuse Services.

Phase One involved a grounded theory, multi-site qualitative design to identify the person-in-environment factors that help or hinder recovery for people experiencing severe and persistent mental illness. Nine SMHAs used purposive sampling to recruit 115 consumers that participated in 10 structured focus groups. Researchers used rigorous, constant and comparative analytic methods involving qualitative coding, codebook development, cross coding and recoding of the focus group transcripts to develop a single set of findings. All nine SMHAs conducted member checks with focus group participants regarding the coding report for their respective focus group. The research achieved a “confirmability index” (agreement that the coding captured the original content) of 99.47% among the 59 who responded (51% of the original sample).

A conceptual paradigm for organizing and interpreting the phenomenon of mental health recovery emerged from the findings. While recovery is a deeply personal journey, there are many commonalities in people’s experiences. Recovery is facilitated or impeded through the dynamic interplay of many forces that are complex, synergistic, and linked. Recovery is a product of dynamic interaction among characteristics of the individual (self-agency, holism, hope, a sense of meaning and purpose), characteristics of the environment (basic material resources, social relationships, meaningful activities, peer support, formal services and staff), and the characteristics of the exchange (hope, choice, empowerment, referent power, independence, interdependence). Each of these emergent domains/themes contain a rich and complex network of helping and hindering elements.

In Phase Two, the research team used these findings to develop recovery oriented performance indicators. Two sets emerged, 73 consumer self-report data items and 30 administrative data items. In partnership with the participating states, the team refined the self-report set based on consumer review (a Think Aloud process) and a readability check and then conducted a prototype indicator test involving a diverse cross-section of 219 consumer/survivors in seven states. The research team then used the prototype self-report data results to evaluate each item as to: (a) importance rating, (b) factor loading values within a varimax rotated component matrix, (c) response scale distribution and direction, (d) Phase One originating theme, (e) items assessing similar content, (e) clarity of wording, and (f) Phase One member check priorities. Selected demographic variables (e.g., housing status; parent status, etc.) were also cross-tabbed with selected item importance mean ratings to determine whether significant differences exist and therefore if an item should be retained or specified for a particular subpopulation.

The research team generated specific measure definitions (i.e. numerators and denominators) for the administrative data items. The 10 participating SMHAs and the National Association of Consumer/Survivor Mental Health Administrators (NAC/SMHA) were then surveyed on the administrative data items as to (a) the feasibility of implementing each, (b) the importance of each for improving system recovery orientation, (c) whether or not the data articulated in the definition was currently being collected, and (d) specific comments on each. Nine SMHAs and three NAC/SMHA members responded. Through a series of teleconferences the research team evaluated each measure as to importance rating, feasibility rating and comments.

These analyses led to further refinement with a concentrated effort towards parsimony, resulting in 42 self-report items being crafted into an adult consumer self-report survey, and 23 administrative-data items into an authority/provider profile for the Recovery Oriented System Indicators (ROSI) measure. A factor analysis of the 42 self-report items resulted in domains of Person-Center Decision-Making & Choice, Invalidated Personhood, Self-Care & Wellness, Basic Life Resources, Meaningful Activities & Roles, Peer Advocacy, Staff Treatment Knowledge, and Access. The 23 administrative-data items also include the domains of Peer Support, Staffing Ratios, Consumer Inclusion in Governance, and Coercion.

The ROSI bridges the gap between the principles of recovery and self-help—choice, hope, purpose, relationships, self-determination, empowerment, citizenship, resources, opportunities—and the real-world application of these principles in the everyday work of staff and service systems. The ROSI is targeted for large-scale pilot testing. A subset of these items are being incorporated into the Mental Health Statistics Improvement Program Quality Report Version 2.0, the Decision Support 2000+ and other national data collection requirements in order to generate comparable data across state and local mental health systems.

For further information: The Phase One Technical Report, a.k.a. Mental Health Recovery: What Helps and What Hinders? A National Research Project for the Development of Recovery Facilitating System Performance Indicators, is available through NTAC at www.nasmhpd.org/publications.cfm#techreports The Phase Two Technical Report is being written and NTAC hopes to release this by the end of the calendar year. If you are interested in serving as a site for the pilot test, please contact Steven Onken at so280@columbia.edu