
Mental Health Recovery: What Helps and What Hinders?

A National Research Project for the Development of Recovery Facilitating System Performance Indicators

Phase II Technical Report: Development of the Recovery Oriented System Indicators (ROSI) Measures to Advance Mental Health System Transformation

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Phase II Technical Report: Development of the Recovery Oriented System Indicators (ROSI) Measures to Advance Mental Health System Transformation

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Phase I of this national research project provided the foundation for the work of Phase II and would not have been possible without the Phase I research partners and sponsors. To see a complete list of Phase I partners and sponsors, refer to Endnote (1).

The materials herein do not necessarily reflect the positions or policies of any of the research sponsors and partners. The materials are based on the cumulative perspectives and responses of the Phase I and Phase II participants, as analyzed and interpreted by the five-member Research Team.

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Executive Summary

Mental Health Recovery: Helps and What Hinders? A National Research Project for the Development of Recovery Facilitating System Performance Indicators evolved from collaborative efforts among a number of State Mental Health Authorities (SMHAs) and national organizations. These states and organizations were interested in developing a measure related to recovery as one means to assess the performance of state and local mental health systems and providers. The specific aims of this project were as follows:

- ◆ to increase the knowledge base as to what facilitates or hinders recovery from psychiatric disorders and disabilities;
- ◆ to devise a core set of system-level performance indicators that measure critical elements and processes of recovery facilitating mental health programs and delivery systems; and
- ◆ to integrate items that accurately assess recovery orientation into public as well as private local, regional, state, and national efforts for generating informative and comparable data as one means to encourage the evolution of a recovery-based mental health system.

Synopsis of the Phase II Technical Report

This technical report describes the work of the second phase of the National Research Project for the Development of Recovery Facilitating System Performance Indicators. In Phase II, the Research Team, along with several partners, devised system-level indicators to measure the recovery orientation of mental health programs and systems. The work of Phase II included designing and refining a self-report survey to be completed by service recipients, as well as a profile of administrative performance indicators to be completed by mental health agency staff. The Team named this survey and profile ROSI, for Recovery Oriented System Indicators. The ROSI consists of a 42-item consumer¹ self-report survey and a 23-item administrative data profile that gather data on experiences and practices that enhance recovery and those that tend to hinder recovery.

As part of a larger shift toward a recovery paradigm in the mental health field, the ROSI meets a critical need. Performance measurement is increasingly used as a tool for managing behavioral health systems to establish and foster accountability. There is increasing demand for a recovery orientation in public and private mental health programs and systems. The ROSI applies performance measurement to recovery orientation. Concurrently, there is a greater recognition of the value of and need for consumer input and consumer driven mental health systems. The

¹ People use many different terms to describe themselves. In this document, we often use the term “consumer” to denote those who are the primary users of mental health services. We use “consumer/survivor” as well, to reflect the range of terms people use. The term “consumer/survivor” also acknowledges that some people see themselves as survivors of treatment and the experience of having become a person with a psychiatric history. Sometimes we say “person with a psychiatric disorder or disability.” While we recognize that there is no one right term and that terms may be contested, we want to acknowledge the unique experience of coming to psychiatric or mental health treatment. We hope that our research processes and descriptions honor the fact that individuals are first and foremost persons. It may be that the use of the term “consumer” reflects more where mental health services are heading in embracing recovery: toward freedom and choice in services. We ask for your understanding in our use of the various terms.

development of the ROSI has included significant participation by mental health consumers at every step in the process.

Development of the ROSI

This report describes the primary processes used to develop the ROSI, summarized as follows:

- ◆ Generation of indicators based on the findings of Phase I;
- ◆ Prototype test and review of 73 self-report indicators with 219 respondents from seven partnering states;
- ◆ Critical feedback survey on the 19 administrative indicators and 30 corresponding operational definitions with nine partnering states and three state/regional directors of consumer affairs; and
- ◆ Subsequent refinement, contraction, and editing of the indicators.

The following specific steps were taken to strengthen these primary processes:

An initial item writing workshop during which the Research Team brainstormed indicators in response to each domain/theme and subtheme of the Phase I findings.

A face-to-face meeting and a series of teleconferences during which the Research Team brainstormed and then refined and edited the indicator items, including selecting response scales and operationalizing numerators and denominators.

A consumer workshop held at Alternatives 2002 during which 45 participants responded to and gave feedback about a subset of proposed indicators.

An all-day think-aloud session with 10 diverse volunteer consumers to strengthen the self-report items and determine whether the interpretation of the items was congruent with the intended meaning and relatively consistent among the respondents.

Refinements of the self-report items on the basis of the think-aloud feedback and wording suggestions provided by SMHAs.

Assessment of the reading level of self-report items and subsequent refinement of the wording, resulting in a one grade-level reduction to an average 6.1 grade reading level.

Operational definitions of the administrative indicators at the authority level as well as the provider level where relevant.

Overview of Prototype Test and Review of the Self-Report Indicators

Seven SMHAs (Arizona, Colorado, Hawaii, Oklahoma, Rhode Island, South Carolina, and Texas) recruited 219 respondents to test the 73-item prototype self-report survey. The SMHAs took steps to target the involvement of consumers who are often underrepresented (e.g., people who are homeless, people with dual diagnosis, young people, and people from minority populations). States administered the survey to consumers individually, in groups, or through a combination of approaches. Participants were asked to answer demographic questions about themselves and their mental health condition and then complete three steps: respond to each item, rate the importance of each item, and circle any unclear words or phrases.

Responses to the prototype survey were subjected to statistical analyses. The reliability or internal consistency of the items was assessed using Chronbach's Alpha, one of the most commonly used reliability coefficients. The Chronbach's Alpha for the 73 items was .96, which is considered very high. A factor analysis of the 73 items resulted in an eight factor solution that was used as one input into a decision-making process concerning whether to retain or delete a given item. The higher the factor loading, the more likely it was that the item was retained.

Importance ratings were attained from 217 of the 219 respondents. The ratings were done on a scale that ranged from 1 to 10, where 10 meant that the item was most important. The mean or arithmetic average was obtained for each item. The mean scores for the items ranged from 6.94 to 9.14. Thus, all items were rated relatively high, indicating that the respondents viewed all of the items as quite important.

The prototype test results were used to trim the number of questions on the survey. A subgroup of the Research Team reduced the number of indicators from 73 to 41 by using a broad array of criteria that included statistical analyses of the factor structure, mean importance ratings, response scale distribution and direction, maintenance of adequate coverage of Phase I themes, Phase I respondents' priorities, clarity of wording, and content similarity between items. The full Team reviewed this work in teleconferences, and one dropped item was returned to the item set.

A factor analysis was conducted on the reduced 42-item self-report question set, resulting in an 11 factor solution that was then collapsed into eight components:

- ◆ person-centered decision making and choice,
- ◆ invalidated personhood,
- ◆ self-care and wellness,
- ◆ basic life resources,
- ◆ meaningful activities and roles,
- ◆ peer advocacy,
- ◆ staff treatment knowledge, and
- ◆ access.

The reliability coefficient or Chronbach's Alpha computed for the reduced data set of 42 items was .95. While the Team has some confidence that this estimate may be an upper bound estimate of reliability, the Team will pursue in Phase III of the National Research Project the extent to which "does not apply" responses (counted as missing data and thus excluded) influence reliability.

A 10-item subset of the resulting ROSI Self-Report Survey was submitted to the Mental Health Statistics Improvement Program (MHSIP) for inclusion in the Quality Report Version 2.0. The Research Team selected these items based on the factor analysis of the 42-item set and by rating the importance of the items using a Q-sort (queue sort) process. The 10-item subset is being advanced in conjunction with the full 42-item ROSI Self-Report Survey. Further work will be needed to create a psychometrically sound short form of the ROSI.

Overview of the Refinement of the Administrative-Based Indicators

The Research Team generated 30 specific operational definitions (i.e., numerators and denominators) for 19 administrative data indicators. The Team crafted a survey incorporating the indicators and corresponding operational definitions with regard to (1) the feasibility of implementing each; (2) the importance of each for improving system recovery orientation; (3) whether or not the data articulated in the definition were currently being collected; and (4) specific comments on each. Nine participating SMHAs and four members of the National Association of Consumer/Survivor Mental Health Administrators (NAC/SMHA) completed the survey. The Team used the findings to further refine the administrative data indicators, with a concentrated effort toward parsimony, resulting in 16 indicators and 23 corresponding operational definitions being crafted into an authority/provider administrative data profile. The 16 indicators and 23 corresponding administrative data measures include the domains/themes of peer support, choice, staffing ratios, system culture and orientation, consumer inclusion in governance, and coercion.

Limitations

Limitations of the study include the fact that the prototype sample is not fully representative of the target population of persons receiving public mental health services. Greater variation, however, was achieved in the Phase II respondent pool than in the Phase I sample. The qualitative research methodology of Phase I limited the ability to discern the relative importance of the Phase I domains/themes and subthemes. The Phase II participants rated the importance of each indicator (indicators were based on Phase I domains/themes and subthemes), which provided the Team with an average importance rating for each indicator. While promising, the results of the prototype factor analysis should be viewed as tentative because of the small size of the sample relative to the large number of questions asked. The factor structure of the proposed 42-item Self-Report Survey will need to be examined further in Phase III research, using a larger data set.

Plans for Phase III

In the proposed Phase III of the National Project, the Research Team hopes to pilot test the Consumer Self-Report Survey and the Administrative Data Profile that, together, make up the ROSI. Pilot testing the ROSI will serve several functions: The psychometric properties of the ROSI Survey will be evaluated further; the Administrative Data Profile will be tested; the potential for benchmarking program performance will be explored; and a user's manual will be prepared to guide systems using the measures.

Administrators, agencies, evaluators, consumer leaders, and advocates are invited to participate in the development of a multisite pilot of the ROSI measures by contacting either of the co-principal investigators. Any organization that plans to use the ROSI without being part of the formal pilot test is asked to notify the Research Team in advance. The Team requests that the ROSI Self-Report Survey and Administrative Data Profile be used as currently formatted and operationalized; that the organization collect a small set of consumer demographics and agency level descriptors; and that the organization be open to possible sharing of its de-identified data with the Research Team. These steps will allow refinement of the ROSI measures over time and will advance the

field's understanding of the facilitation and impact of a recovery orientation in mental health programs and systems.

Mental Health Systems Transformation and the ROSI

The ROSI measures are potentially strong tools that can be used to inform and guide system transformation efforts. Some of the ways the ROSI tools could be used include the following:

- ◆ to create a baseline data set to assess the current status of the recovery orientation of a program or local system;
- ◆ to set specific benchmarks that target desired increments of progress toward achieving a recovery orientation;
- ◆ to measure change over time in the recovery orientation of the program or system;
- ◆ to compare the performances of provider agencies;
- ◆ to sensitize and educate mental health providers about important factors that facilitate or impede recovery; and
- ◆ as part of other targeted studies of mental health recovery, to develop a better understanding of how agency or system-level performance on key indicators relates to other recovery elements, processes, or outcomes.

We want to thank those who have participated thus far in bringing the ROSI measures to fruition. The ROSI measures have been carefully and rigorously developed and are grounded in the lived experience of people who use mental health services. They provide new means to assess service performance and listen to the voice of consumers. The ROSI measures can be used as tools to transform systems of care so that recovery becomes an increasing reality in the lives of Americans with psychiatric disabilities. To view the ROSI Self-Report Survey and Administrative Data Profile, please see the ROSI measures in Appendix G and J.

Part I. The Context of the National Project: Introduction and Overview

Mental health systems in America increasingly face the demand that they transform to operate from a recovery orientation and to deliver services and supports in ways that facilitate and promote the process of recovery in the lives of the people they serve. To fulfill this mandate, programs and systems need to have a set of management tools and sound measures that allow them to increase their knowledge about the degree to which they are operating from a recovery orientation, how well they are performing, and the impact of recovery facilitating programs and services.

Mental Health Recovery: What Helps and What Hinders? A National Research Project for the Development of Recovery Facilitating System Performance Indicators has developed a set of performance measures that state and private mental health agencies, administrators, research and evaluation staff, consumer advocates, and others can use to assess the recovery orientation of local and regional mental health programs and systems. This technical report informs stakeholders who are committed to transforming their mental health systems about Phase II of the National Project. The report describes the rigorous processes that were used to create sound performance indicator tools, presents the resulting tools and what we know so far about their use, and suggests roles that these tools can play in the transformation of local, regional, and state mental health systems.

This report is formatted in a manner that also allows a reader to gain a general overview of the project and uses a series of footnotes to reference endnotes and electronic links for more in-depth information. For example, endnotes provide more detail on Phase I findings, transformation of mental health systems, and other recovery measures. Specified electronic links include web addresses to the National Research Project Phase I Report as well as the Mental Health Statistics Improvement Program (MHSIP).

The first section of the report offers a short introduction and overview of the National Research Project for the Development of Recovery Facilitating System Performance Indicators. It includes a brief history of the project and describes the project's mission and aims, the three phases of the project, and the activities and products associated with each phase. This material is followed by a discussion of three important contextual issues that influenced the work of the project: (1) the shift to a recovery orientation; (2) the growing importance of performance measurement in the management of behavioral health systems; and (3) the importance of consumer voice in the mental health system. This section is followed by a brief review of Phase I of the project and the Phase I findings.

The core of this report is a detailed description of Phase II activities. These sections describe the project's Phase II work to create and refine a rigorous set of recovery performance indicator tools—the Recovery Oriented System Indicators (ROSI) measure—that include a 42-item ROSI Self-Report Survey and a 23-item ROSI Administrative Data Profile. The final sections of this report include preliminary thinking about Phase III and describe how stakeholders can use these tools in their efforts to transform their local, regional, or state mental health system.

A Brief History of the National Project

Mental Health Recovery: What Helps and What Hinders? A National Research Project for the Development of Recovery Facilitating System Performance Indicators evolved from the collaborative efforts of a number of SMHAs, several national organizations, consumer/survivor leaders, and mental health recovery researchers, all of whom were interested in identifying or creating a sound and useful research instrument to measure the performance of mental health systems in terms of mental health recovery.

Representatives of several SMHAs, along with mental health consumers from those states, a small expert panel of recovery researchers, and staff members from the Center for Mental Health Services (CMHS) and the National Association of State Mental Health Program Directors (NASMHPD) met in May 2000 in Austin, Texas. After reviewing the existing research, meeting participants determined that a need existed for a new instrument or set of measures that could validly and reliably assess the performance of local and regional mental health systems and provider agencies, one that would allow the collection of comparable data on the recovery orientation of programs and systems. Subsequent teleconferences resulted in the launching of the National Research Project under the direction of the five-person Research Team (i.e., Onken, Dumont, Ridgway, Dornan, and Ralph), and Phase I was implemented in early 2001. Through the course of Phase I and Phase II, additional SMHAs became involved as research partners in the National Project, and additional organizations provided sponsorship and funding to support the work of the project. The title page of this technical report lists the Phase II partners and sponsors, and Endnote (1) lists Phase I partners and sponsors.

The Project Mission

The mission of the National Research Project is to develop the knowledge, means, and tools needed to identify, develop, and use performance indicators to determine the degree to which a given mental health system engages in activities that facilitate or hinder recovery in the people the system serves.

The project has three specific aims:

1. To increase the knowledge base regarding what facilitates or hinders recovery from psychiatric disorders and disabilities;
2. To devise a core set of system-level performance indicators that measure critical elements and processes of recovery facilitating mental health programs and delivery systems; and
3. To integrate items that accurately assess recovery orientation into public and private, local, regional, state, and national efforts to generate informative and comparable data, as one means of encouraging the evolution of a recovery-based mental health system.

The Three Phases of the Project

The work of the National Research Project has been undertaken in three major phases. Phase I involved building the knowledge base with regard to what helps or facilitates mental health recovery and what hinders the recovery process. Phase I used qualitative research methods to explore helping and hindering elements from the perspective of a diverse group of people across the country who have experienced psychiatric disorders or disabilities. The results of Phase I were published as a research report, *A National Study of Consumer Perspectives on What Helps and Hinders Recovery*. This report advanced the definition and conceptualization of mental health recovery and, in particular, articulated the personal and environmental factors that help and hinder recovery. Part III of this report provides more information on Phase I. The full Phase I report is available online².

Phase II of the National Research Project involved devising a set of performance indicators to measure the recovery orientation of mental health programs and systems. The Research Team designed and refined a self-report survey to be completed by service recipients and devised a set of administrative performance indicators to be completed by mental health agency staff. Phase II also included a review and test of a prototype of the consumer self-report survey, as well as collection of feedback on the proposed administrative indicators. The ROSI, consisting of the ROSI Consumer Self-Report Survey and ROSI Administrative Data Profile, evolved from these activities. This report primarily details the efforts of Phase II.

In Phase III of the project, the Research Team proposes to field test the ROSI measures and methods, and finalize the ROSI. Phase III research will include assessing the validity, reliability, soundness, and other statistical properties of the ROSI and creating a user's manual.

Context of the National Project

Three important contextual factors have influenced the work of the National Project. The first factor is the increasing demand for a recovery orientation in public mental health systems, which is part of a larger shift toward a recovery paradigm in the mental health field. The second major contextual factor is the increasing use of performance measurement as a tool for assessing and managing health and behavioral health care systems. The third factor involves increasing the attention paid to the voice and concerns of mental health consumers and strengthening their roles in planning, implementing, and evaluating mental health services.

Shift Toward a Recovery Orientation in Mental Health Systems

The demand to move mental health systems toward a recovery orientation has grown over the past few decades. Before the 1980s, mental health recovery was a foreign concept to most people working in the mental health field. Until fairly recently, mental health professionals were generally

² The Phase I Research Report is available at <<http://www.nasmhpd.org/>>. Click on "publications," scroll to "National Technical Assistance Center for State Mental Health Planning (NTAC) Publications and Reports," scroll to and click on "Technical Reports" and the report and appendices are under the 2002 listing.

taught that mental disorders were lifelong conditions; a person diagnosed with a mental illness would likely continue to have severe symptoms and decline in functioning over time. The mental health system was seen as primarily serving a maintenance function. In earlier eras, people with psychiatric disabilities were often socially segregated, and most programs tried to suppress symptoms and help people subsist while living a constricted life characterized by serious impairment and chronic disability.

The mental health consumer/survivor movement, which emerged in the early 1970s, challenged the notion that people always remain disabled after having prolonged psychiatric disorder. Several consumer/survivors began discussing, defining, and describing their experiences of mental health recovery (Deegan, 1988; Houghton, 1982; Leete, 1989). Consumer/survivors increasingly wrote and spoke about their own experience of recovery and the recovery of their peers. In fact, recovery had been embedded in consumer writings, activities, and research beginning in the 1930s and can be found in literature as early as the 1770s. What was increasingly becoming clear, however, was that people with prolonged and serious psychiatric disorders were regaining the ability to live full lives, and some were becoming leaders and spokespeople for consumer empowerment. People with psychiatric disabilities protested the poor quality of many of the available services and the mental health system's orientation toward chronic care. People with psychiatric disabilities sought full rights of citizenship and a place in their community, and they demanded consumer representation on local committees and boards, state planning committees, and national grant panels.

The fact that most people with psychiatric disabilities do recover over time was also demonstrated in the findings of several large-scale, long-term outcome studies conducted around the world (Carpenter & Kirkpatrick, 1988; DeSisto, Harding, McCormick, Ashikaga, & Brooks, 1995; Mueller, Keller, Leon, Solomon, Shea, Coryell & Endicott, 1996). These studies found that half to two-thirds of people who had experienced severe and prolonged psychiatric disorders went on with their lives, were able to function well, often returned to work, and had positive relationships, and many had few or no psychiatric symptoms. The dynamics of the process of personal recovery were examined and described in several well-designed qualitative studies of recovery that listened carefully to people who were experiencing mental health recovery (Davidson & Strauss, 1995).

During the same period, psychosocial rehabilitation programming began to produce positive outcomes that had been thought impossible in an earlier era. Psychosocial rehabilitation programs helped people successfully live, learn, and work in their communities. The idea of recovery was picked up by academicians, who promoted recovery as a potentially powerful driving vision for the mental health field (Anthony, 1993). Interest in mental health recovery spread throughout the mental health community over the course of several years, and for very good reasons. As Ralph (2000b) points out,

Consumers of mental health services who discover that there is such a concept are given hope that they can reach some level of normal life. Providers are realizing that to have their clients recover is to their advantage, not only so that the people they serve can enjoy better health, but also so that they can have enough staff and time to assist those who are coming into the system. Payers for mental health

services (e.g., health maintenance organizations [HMOs], Medicaid) are most interested in being able to reduce services and costs. Those who fund services (e.g., SMHAs, federal programs, legislators) want to see their dollars produce success.

National Attention

In 1999, the Surgeon General of the United States focused on mental health and published a major report. Three consumer/survivors were appointed to participate on a 50-member advisory board that informed the preparation of the report. These individuals, along with other collaborators, produced five background papers on subjects of concern to consumers. One of the reports was on mental health recovery (Ralph, 2000a). As a result of these efforts and growing awareness in the field, mental health recovery was a central concept in *Mental Health: A Report of the Surgeon General* (USPHS Office of the Surgeon General, 1999). The Surgeon General recommended that all mental health systems move toward embracing a recovery orientation.

During this time, several SMHAs became interested in the concept of mental health recovery and began examining how the programs and practices of the formal helping system could support the personal process of recovery (Beale & Lambric, 1995; Jacobson, 1998; Jacobson & Curtis, 2000). Some systems jumped on the bandwagon simply by changing the language they used—many providers and SMHAs began including the word “recovery” in their mission statements and program descriptions. Other states took the need to change the driving paradigm and the operation of their systems much more seriously, and began working hard to reform their mental health systems at a deeper level.

In 2002, George W. Bush appointed the President’s New Freedom Commission on Mental Health to critically examine the mental health system in America; hold a series of hearings across the country to identify problems in the current mental health service delivery system; and formulate a set of specific recommendations to solve these problems. Once again, many people interested in mental health recovery were involved. A consumer movement leader/psychiatrist, Dan Fisher, of the National Empowerment Center in Massachusetts, and a progressive state mental health director, Michael Hogan of Ohio (who chaired the Commission) helped bring the importance of recovery to the forefront.

The Interim Report of the President’s New Freedom Commission on Mental Health found that (1) the mental health system is not oriented toward the single most important goal of the people it serves: hope of recovery; (2) the lack of state-of-the-art treatments results in wasted resources and lost opportunities for recovery; and (3) more people could recover if they had access to treatment and support tailored to their individual needs. In the Commission’s Final Report, *Achieving the Promise: Transforming Mental Health Care in America*, issued in July 2003, recovery was emphasized as a driving concept that should be embraced by every mental health system across America.

Need for Transformation of Mental Health Systems

The New Freedom Commission report contains a vision statement, findings, and specific goals that strongly reinforce the importance of the work done by the National Research Project to Develop

Recovery Facilitating System Performance Indicators. The Commission’s vision statement reads, in part,

We envision a future in which everyone with a mental illness will recover...and... everyone...has access to effective treatment and supports—essential for living, working, learning, and participating fully in the community (p. 1).

The report states that traditional efforts to reform mental health systems are not enough; that there is a need to fundamentally transform how mental health systems perform. The report specifies that the overarching goal of transforming mental health systems must be to promote recovery. The Commission recommended a transformed system based on two major principles. The first is that services and treatments are consumer and family centered, and provide real choices, rather than being operated in a bureaucratic fashion that is often unresponsive to the needs of the individuals served. The second principle is that the system focuses on mental health consumers’ ability to cope with life challenges and on facilitating recovery and building resilience, not only on managing the symptoms associated with psychiatric disorders.

One of the major goals in the report is that mental health care should be consumer and family driven. To achieve this goal, consumers must have individualized plans of care; statewide recovery plans must reflect an aggregate of the needs of individuals; mental health systems should be fully oriented toward recovery; programs should be more accountable to consumers’ needs, preferences, and choices; consumers should be more fully involved in managing their own care; and consumers should be actively involved in planning, designing, redesigning, and evaluating systems of care.

Support for the development of a rigorous means to measure the recovery orientation of local mental health systems has grown significantly since work began on the National Research Project to Develop Recovery Facilitating System Performance Indicators. The increased interest at the federal level in the importance of a recovery orientation—evidenced by the Surgeon General’s Report on Mental Health and the President’s New Freedom Commission report—has led to a much stronger emphasis on promoting the development of recovery-oriented systems of care in the Substance Abuse and Mental Health Service Administration/Center for Mental Health Services (SAMHSA/CMHS).

Federal Agency Support for Mental Health System Transformation

Federal efforts are currently focused on promoting mental health recovery as the driving framework, guiding vision, and mission for public mental health systems. SAMHSA, the federal mental health agency, has as its stated mission “Building resilience and facilitating recovery” as well as ensuring a home, a job, and a life in the community for everyone.

A. Kathryn Power, Director of CMHS, speaks forcefully about the need to transform federal, state, and local mental health systems so that they promote recovery. Power tells audiences that “transformation” implies the need for much more than the traditional reform efforts that have occurred in mental health systems in recent years. Instead, transformation demands profound changes in kind and degree that require new underlying principles, new competencies, and alterations in programmatic approaches (Power, 2003; 2004c). As Power envisions it,

“...in order to work together to reach our destination—a recovery-focused mental health system that will truly serve the needs of all Americans—we need a *common* ground...a language that makes it possible for everyone involved to communicate effectively and to interpret, embrace, and apply these concepts with a shared understanding.... Our collective ability to interpret and apply these concepts is *essential* to transforming our system into one that is recovery based” (Power, 2004a)³.

To create such a shared understanding, SAMHSA/CMHS and other national organizations sponsored a number of national conferences on various aspects of recovery in the fall of 2004. These included a meeting on transforming mental health systems, one on recovery and resilience in children’s mental health, one on measuring the promise of recovery, and a national conference to create consensus on the definition of mental health recovery. Clearly, there is heightening interest in the concept of mental health recovery. This focus is part of a larger paradigm shift that is reordering how the mental health system operates.

Recovery Paradigm Shift

The National Research Project has taken place during a time of change in the basic paradigm that guides the mental health field. What do we mean when we say that a paradigm shift is moving the mental health field from a “chronicity” or “deficit” paradigm to a “recovery orientation”? What are some of the changes that are needed in the basic assumptions and working models that guide the operation of mental health programs and systems?

The major changes involved in the shift to a recovery paradigm include a change in the assumptions concerning the outcomes people with psychiatric disabilities can achieve, from one where maintenance was the ultimate goal to one in which growth, resilience, and the reclamation of a full and productive life are possible and even likely. The new paradigm implies a shift in who has a say in setting goals and designing plans of treatment; this shift requires systems to more fully honor consumers’ needs and preferences. It requires the creation of a consumer driven system, rather than exclusive reliance on professionals to make decisions and set treatment goals for people entering the system, or slotting consumers into rigid programs that do not meet their self-perceived needs. The paradigm shift toward recovery involves a change in the nature of the relationship between the helper and those who are served, to a relationship based on partnership and consumer empowerment rather than on coercion.

The paradigm shift toward a recovery orientation frequently implies the need to change the location where services and supports are provided. Instead of providing services and supports in formal settings, they can be offered to people where they are living, learning, and working in the community. Social segregation on the basis of disability is avoided, and full community integration is encouraged. The major elements of the recovery paradigm shift are summarized in the following table (Ridgway, 1999).

³ To read more remarks by A. Kathryn Power, please refer to Endnote (2).

Table I: Chronicity Paradigm versus Recovery Paradigm

Chronicity Paradigm	Emerging Recovery Paradigm
Diagnostic groupings; “case”; lumped and labeled as “chronic/SPMI/CMI”	Unique identity; whole person oriented; person first language
Pessimistic prognosis; “broken brain”	Hope and realistic optimism
Pathology/deficits; vulnerabilities emphasized; problem orientation	Strengths/hardiness/resilience; self-righting capacities emphasized
Fragmented biological/psychosocial/ oppression models	Integrated bio-psycho-social-spiritual holism; life context
Professional assessment of “best interests” and needs; paternalism	Self-definition of needs and goals; consumer driven; self-determination
Professional control/expert services	Self-help/experiential wisdom/mutuality; self-care/partnership with professionals
Power over/coercion/force; compliance	Empowerment; choice
Reliance on formal supports or total “independence”	Emphasis on natural supports; interdependency; ongoing mutual support
Social segregation; formal program settings; deviancy amplifying artificial settings	Community integration; real-life niches; access and reasonable accommodation to natural community resources/in vivo services and supports
Maintenance/stabilization; risk avoidance	Active growth/new skills and knowledge; dignity of risk
Patient/client/consumer role	Normative roles/natural life rhythms
Resource limitations; poverty	Asset building; opportunities
Helplessness/passivity/adaptive dependency	Self-efficacy/self-sufficiency/self-reliance

Defining Mental Health Recovery for the National Project

Mental health recovery is sometimes viewed as the remission of psychiatric disorder, evidenced by the lessening or absence of psychiatric symptoms or impairment. But recovery is also often described as more than, or different from, clinical remission. Recovery can be seen as achieving a positive sense of self in spite of continuing symptoms and as a process of surmounting the social effects associated with the experience of psychiatric disorder or disability (Crowley, 2000; Deegan, 1996; Onken, Dumont, Ridgway, Dornan, & Ralph, 2002; Ridgway, 1999). The self-management of psychiatric symptoms is often highlighted as a cornerstone of recovery, but recovery can take place despite the fact that a person continues to have psychiatric symptoms; recovery is widely regarded not as a “cure” but rather as an ongoing process of healing and of reclaiming a full life (Anthony, 2003; Crowley, 2000; Deegan, 1996; Kramer, 2002; New Freedom Commission on Mental Health, 2003; Ridgway, 1999).

The National Research Project to Develop Recovery Facilitating System Performance Indicators based its work on a broad definition of recovery that views the recovery process in an ecological framework. The Research Team blended several existing definitions and concepts of recovery into the project’s definition of mental health recovery:

Recovery is an ongoing, dynamic, interactional process that occurs between a person's strengths, vulnerabilities, resources, and the environment. It involves a personal journey of actively self-managing psychiatric disorder while reclaiming, gaining, and maintaining a positive sense of self, roles, and life beyond the mental health system, in spite of the challenge of psychiatric disability. Recovery involves learning to approach each day's challenges, to overcome disabilities, to live independently, and to contribute to society. Recovery is supported by a foundation based on hope, belief, personal power, respect, social connections, and self-determination (Onken, Dumont, Ridgway, Dornan, & Ralph, 2002, pp. 2–3).

There is clear need for mental health systems to embrace the vision, practices, and goals of recovery, and the National Research Project has developed tools to help stakeholders learn about the recovery orientation of the local or regional system and plan needed transformation.

Growing Emphasis on Performance Measurement in the Management of Behavioral Health Systems

The growth in the importance of recovery coincides with the movement toward increased attention to performance measurement in health, mental health, and behavioral health care systems. Performance measurement is broadly the act or process of determining how well, or the extent to which, a system, organization, or agency is operating or functioning, usually with regard to effectiveness and especially as determined by a formal standard. The use of performance measurement is a relatively recent phenomenon in the mental health field.

Performance measurement became much more influential in the 1990s as a part of broader efforts to reform health and behavioral health care systems. Performance measurement methods are emphasized as a part of the increasing demand for accountability for the *quality and impact* of the services and care that are delivered, not just financial accountability for the *cost* of the services delivered (Mandersheid, 1998). With the widespread implementation of health care reform in the behavioral health care sector, public oversight has become increasingly critical. Health care and mental health care reform have a dual aim of controlling costs and improving the quality of care. Performance measurement can inform four interrelated types of accountability: (1) accountability for practices; (2) accountability for outcomes; (3) accountability for plan performance; and (4) accountability for system performance (e.g., indicators that reflect how large scale systems are operating) (Mandersheid, 2004). Performance measurement provides managers with tools they can use to target necessary improvements and sometimes provides information to inform cutback decisions or cost containment efforts.

The evolution in accountability measures is associated with the increased need to demonstrate the effectiveness of all types of social service programs. The Government Performance and Results Act of 1993 (P.L. No. 103-62) requires government at all levels to establish performance measures for all federally funded programs in the United States. Performance measurement approaches help clarify what service delivery systems seek to achieve; identify and document the contributions programs make toward the achievement of social goals; and document what people are getting in return for their investment of public dollars.

Health care and some mental health care organizations and government entities have also used performance measurement techniques to gather and publish data that allow corporate purchasers, state agencies, and consumers of services to compare the performance of systems and, sometimes, to compare the performance of competing health plans. Some of the documents that have been developed to summarize important performance indicators are called “report cards.” “Practice and outcome measures can be aggregated in report cards. Report cards can be aggregated and included in broader system performance measures” (Mandersheid, 2004, p. 2).

Mental Health Statistics Improvement Program (MHSIP) Performance Measurement Efforts

From its inception, the National Research Project to Develop Recovery Facilitating System Performance Indicators has been associated with the performance measurement efforts of the Mental Health Statistics Improvement Program (MHSIP). MHSIP is a community of people who share the belief that improvements in mental health services can occur when decision makers—including service providers, those who pay for services, and those who receive them—make rational decisions on the basis of objective, reliable, and comparable information about those services.

What is the MHSIP community? The MHSIP community has been around since the 1970s; the community develops rules for the collection of mental health data, advises the federal government on data issues, and develops and implements projects to improve mental health data across the nation. The MHSIP community provides guidance and technical assistance on the design, structure, content, and use of mental health information systems. MHSIP efforts provide uniform, comparable statistical information about mental health services that enables broad-based research on systems of care and models for service delivery. MHSIP’s current mission is to foster and enhance the quality and scope of information for decisions that will improve the quality of life and recovery of people with mental illness. (For more information on MHSIP, visit <www.mhsip.org>.)

The MHSIP community created the MHSIP Consumer-Oriented Mental Health Report Card in the 1990s, emphasizing the consumer-oriented system focus, to assess the quality and cost of mental health and substance abuse services (MHSIP Task Force, 1996). CMHS developed a grant program for states to implement mental health performance measurement systems, using the indicators and measures in the MHSIP Report Card as a model. One of the measures was the MHSIP adult consumer self-report survey. This survey asked consumers about their perception of care and included items regarding access, outcomes, appropriateness, quality, and satisfaction with mental health services. The first report card was released in 1996; it was intended to serve as a measure that could standardize data collection across the United States.

The 5-state feasibility study and the 16-state indicator project sponsored by CMHS advanced the operationalization and testing of many of the indicators proposed in the MHSIP Report Card. While consistency and commonality of information were found to be important, these studies have yielded other valuable findings, such as the fact that different measures are needed for different populations in different settings. Guided by these findings and other ongoing efforts, new

instruments and measures have been developed to refine and enhance the original MHSIP Report Card. For example, instruments related to children’s mental health and inpatient settings are currently being developed and tested.

Building on the lessons learned from the first report card, the MHSIP community is developing the next generation of behavioral health performance measures in the MHSIP quality report. In recognition of the fact that performance measurement provides an opportunity to introduce important values into systems that monitor activities, the MHSIP quality report is values-based—key values and expectations of the mental health system are implicit in the measures. These include the importance of quick and easy access to clinically sound and culturally appropriate services for consumers and their family members; access to state-of-the-art services that are appropriate and responsive to individual needs and preferences; improved availability of treatment and support services that address the problems and concerns for which services are sought; and services that do no harm.

This development of the next generation of behavioral health performance measures was launched, in part, to maintain the momentum in efforts to build a consumer driven, consumer focused system that helps mental health consumers move in the direction of recovery. Thus, the development of recovery measurement tools has been targeted in the MHSIP community in recent years, and the National Research Project to Develop Recovery Facilitating System Program Indicators has been an important part of several broader efforts to develop recovery indicators. The National Research Project was sponsored, in part, under the auspices of MHSIP. The project’s development of performance indicators related to mental health recovery has been central to MHSIP efforts to develop a revised and updated quality report. The work of the National Research Project has been coordinated with that of MHSIP, and Research Team members have been active contributors to the MHSIP community efforts. The final version of the MHSIP quality report will include indicators and measurement items based on the ROSI.

Other Efforts to Measure Mental Health Recovery

The National Research Project to Develop Recovery Facilitating System Program Indicators is one among several efforts to measure recovery. There is a growing emphasis on recovery measurement in the mental health field, but this area is relatively new, and few instruments exist to measure recovery compared with the number of measures available to measure other aspects of mental health. For example, there are many scales that assess symptoms of psychiatric disorder, quality of life, level of functioning, and depression.

A review of recovery instruments conducted in 2000 (Ralph, Kidder, & Phillips) identified eight recovery measures, and most of them were found to measure something *about* recovery rather than recovery per se. Some surveys were made up of open-ended questions used in qualitative studies to gather data to help define recovery or to gather people’s perceptions about recovery. Three instruments measured attitudes or personal visions of recovery; two were qualitative question sets geared toward defining recovery; and three provided rating scales that could result in the measurement of aspects of recovery. All the instruments asked for responses from mental health consumers. Some of the instruments were developed as a part of a doctoral dissertation, and the research has not continued. Most of the instruments were works-in-process, and no information

was available on how these measures might assess change over time or how they might measure the impact of a particular recovery-oriented intervention. All the measures reviewed by Ralph and colleagues attempted to measure personal recovery and had little to moderate content related to how mental health systems or services influence the recovery process.

It is important for the field to have several good personal-level and system-level measurement tools to more fully understand the process of recovery and the impact of both personal and system change. It is likely that measuring individual recovery and measuring the recovery orientation of mental health systems are complementary undertakings. The two types of measures could be used together to assess the impact of mental health system transformation on personal recovery and to identify outcomes in personal recovery that are associated with changes in the operations of formal service systems.

A follow-up compendium of recovery measures was recently compiled by the Human Services Research Institute (HSRI). This compendium⁴ reviews earlier efforts to measure recovery and expands the measures to program and system-level instruments⁵.

Recovery measurement is complex. Measurement models must acknowledge that recovery is a dynamic state and is, to a great degree, a unique process for each individual. Recovery is not necessarily a one time experience that follows a predictable or linear course. Instead, people in recovery can experience setbacks, and recovery can be experienced in many ways or many times over the course of a lifetime. Knowing that setbacks are part of the recovery process and that a person may experience more than one turnaround on the way to recovery may enable behavioral health systems and staff to be more understanding and increase their ability to help consumers lengthen, broaden, and deepen their experience of recovery.

The Movement to Increase Consumer Voice in Planning, Implementing, and Evaluating the Mental Health System

Accountability in complex systems of care has been long in coming. It has been especially challenging to establish measures of accountability that include or fully represent the voice and viewpoints of primary stakeholders in the mental health system: people who have psychiatric disorders or disabilities and who are the direct consumers or “customers” of mental health services. The lack of attention to mental health consumer perspectives reflects a long history and culture of oppression in mental health systems; systems that were historically organized to care for, control, and socially segregate rather than to rehabilitate, empower, and socially integrate people with psychiatric disabilities into the mainstream of life (Harding & Zahniser, 1994; NCD, 2000; Rapp, 1998; Ridgway, 1988).

There is a growing awareness of the importance of attending to the views, perspectives, self-perceived needs, and preferences of consumers of public mental health services (Ridgway, 1988).

⁴ *Measuring the Promise: A Compendium of Recovery Measures, Volume II* (2005) prepared by Campbell-Orde, Chamberlin, Carpenter, & Leff is available at <<http://tecatsri.org/PN-55.pdf>>.

⁵ To read about some of these recent examples of recovery measurement approaches that look at personal recovery or system-level indicators of a recovery orientation, see Endnote (3).

The perspectives and priorities of mental health consumers often differ greatly from those of service providers (Campbell, 1998a; Ridgway, 1988). Mental health professionals often cite as their highest priorities controlling the symptoms and behavior of consumers and maintaining the effectiveness of the service system (Scott, 1993). The goals and priorities of providers are often in conflict with the recovery orientation that is increasingly promoted by consumer leaders, advocates, and peer run organizations (Campbell, 1998a). Wide differences exist regarding needs and preferences for services and supports, the barriers that exist to obtaining them, and the relative importance of treatment goals (Campbell, 1998a; Ridgway, 1988).

It is increasingly recognized that mental health consumers can live meaningful and successful lives and that they have a strong tendency toward resilience or rebound that is often overlooked or ignored by programs and systems. Consumer resistance to—even rejection of—traditional mental health services and the increasing availability of alternative consumer designed and delivered services merit attention, especially as these alternative approaches are increasingly demonstrating their effectiveness. Empirical studies show that consumer designed and delivered services support active coping and positive outcomes (Campbell, 1998a; Campbell, 2004).

Chowanec, Neunaber, and Krajl (1994) report that despite an increase in rhetoric expressing support for the adoption of client-centered and client-driven approaches in public mental health systems, mental health consumers still must overcome tremendous personal and political barriers to have their voices heard and their expertise valued in the direction or assessment of services. These authors observe that “within the field of health care—and particularly mental health care—perhaps the most far-reaching revolution will be the reorientation and reconceptualization of the role of the patient within the health care delivery system” (p. 47).

In the past, consumers seldom had an impact on research, because people who experience psychiatric disorders were excluded from the work of generating research questions, constructs, and theories, and from the process of designing the methods and ideas that guide research investigations (Kaufmann & Campbell, 1995). As is true for other historically marginalized groups, people with mental illness were often excluded from “the means to participate in creating forms of thought relevant or adequate to express their own experience or to define and raise social consciousness about their situation” (Personal Narratives Group, 1989, p. 19). In fact, until recently, mental health consumers had largely been excluded from the “circle of talk” that produced the guidelines and principles that shaped mental health service delivery systems, the systems’ supporting institutions, and the evolution of the underlying ideas that governed how their needs were understood. As a result, little data regarding consumer-valued services, supports, and outcomes were collected or analyzed by mental health systems (Campbell, 1998b). Token input and observations made by people who do not have the experience of psychiatric disorder cannot provide an authentic or full representation of the range of opinions, self-perceived needs and preferences, judgments, and experiences of diverse consumers (Campbell, 1997).

Even when consumers were invited to contribute, those who were asked to speak about the experience of psychiatric disorder often faced the barrier of having to legitimize their expertise, competence, and the messages they sought to impart (Kaufmann & Campbell, 1995). People in recovery were often asked to respond to an agenda established by others. A small group of people

were repeatedly asked to speak from the “consumer perspective,” as though all people with psychiatric disorders shared common views that could be adequately captured by listening to the opinions of a few key people (Kaufmann & Campbell, 1995).

The growing understanding that knowledge is power led researchers to raise questions such as these: Who does this research empower? Whose voices does it amplify? Whose points of view does it champion? Who is generating this knowledge? Who has access to this knowledge? Who determines how the knowledge will be used? (DePoy, Hartman, & Haslett, 1999; Rappaport, 1994). The idea that involvement in research can empower members of oppressed groups has begun to reshape the way research is conducted (DePoy, Hartman, & Haslett, 1999; Rapp, Shera, & Kisthardt, 1993).

Until recently, the mental health professions tended to assume that quantitative research was the best means to understanding human behavior (Corrigan & Garman, 1997). Other methods of research are increasingly viewed as making valuable and valid contributions to collective thinking about a variety of social problems. Qualitative research, including naturalistic inquiry, strives to capture the complexity of issues directly from the perspective of people who experience them (Lincoln & Guba, 1985). Participatory action research methods facilitate social action through social inquiry (DePoy, Hartman & Haslett, 1999). Consumer empowerment is developing its own set of research strategies (Rapp, Shera & Kisthardt, 1993). Research methods that seek to understand the standpoint of people who have been oppressed help us understand the relationship between knowledge and power (Harding, 1996).

Approaches that help people create a shared vision or understanding through social science research acknowledge that the expression of ideas is an important and powerful social and political act. The ability to give expression to one’s experience gives one voice; giving voice to people who have been oppressed helps people develop a sense of self (Belenky, Clinchy, Goldberger, & Tarule, 1986). Research projects can encourage people to share parts of their experience or their personal stories; there is power in oral history, storytelling, and the sharing of personal experiences—such acts humanize people in significant ways (Kaufmann & Campbell, 1995; Ridgway, 2001). Research that incorporates consumer voice can help demystify the experiences of people with psychiatric disabilities and clarify the power relationships that are embedded in their lives (Skillman, 1991). Opportunities for the voice of consumers to be heard can spawn creative inquiries into the nature of psychiatric disorder, the journey of healing and recovery, and how the provision of supports and services can help or hinder this journey (Onken, Dumont, Ridgway, Dornan, & Ralph, 2002; Ridgway, 2001).

New conceptual frameworks emerge when people with psychiatric disabilities are encouraged to articulate their experiences, needs, and desires, and when their ideas and perspectives are valued. The experiential wisdom that mental health consumers possess is increasingly a social force driving improvement and reform in mental health systems (Campbell, 1997). Consumer respondents provide information about situations, conditions, concerns, and the impact of treatment that cannot be provided by other stakeholders or mental health professionals. Consumers can provide a range of examples of difficulties they have faced (including difficulties within the

mental health system), the consequences of receiving various forms of treatment, and their personal strategies for coping and recovery.

In the past few years, the growing voices of consumers and their families have begun to play a key role in determining what, where, and how public mental health services are provided (National Technical Assistance Center for State Mental Health Planning, 1997). This shift has generated an increased interest in, and support for, consumer-based research on mental health service needs, priorities, treatment protocols, performance indicators, and desired outcomes; including high quality research conducted by consumers that adds to the general credibility of the consumer voice (Campbell, 1998a; Campbell, 2004; NCD, 2000; Onken, Dumont, Ridgway, Dornan, & Ralph, 2002).

The need to increase consumer involvement in processes of accountability in public mental health has been recognized in a variety of important forums (MHSIP Task Force, 1996; New Freedom Commission on Mental Health, 2003; USPHS Office of the Surgeon General, 1999). Mandersheid (2004), for example, stated that while accountability for the quality of services can mean different things to different people, the point of view of consumers and their families must be ascendant in personal outcome assessment and must be the driver of report card-style efforts to measure the performance of mental health programs and systems.

MHSIP and the Survey and Analysis Branch of the CMHS have included consumer/survivors in the development of performance indicators and outcome measures for some time. For example, focus groups composed entirely of consumer/survivors were sponsored in 1992 (Consumer/Survivor Mental Health Research Policy Work Group Task Force, 1992). Findings from these groups indicated that traditional mental health services pathologize problems in living, are paternalistic, lack a range of desired options, and employ involuntary treatment and more subtle forms of coercion (Campbell, 1997). Evolving, in part, out of the work of the 1992 focus groups, a Consumer/Survivor Mental Health Research and Policy Work Group formed and was active for several years. The work group provided input into the MHSIP Report Card and other measurement efforts.

In 1993 two concept mapping sessions were conducted with consumer/survivors, who recommended that measures should be developed in the areas of legal issues, consumer/survivor impact on service delivery and policymaking, oppression, healing and recovery, coercion/control, personhood, damaging effects of treatment, alternatives (e.g., self-help), citizenship, quality of life, employment, and research (Trochim, Dumont, and Campbell, 1993). The sessions highlighted the need to measure the negative or undesired outcomes associated with mental health treatment, not just the positive outcomes. The concept mapping work also highlighted the importance of measuring system and organization performance and impact along with individual outcomes (Campbell, 1997).

Despite such efforts, attention to the voice of service users has been uneven across the country. The slogan from the disability rights movement that calls for “nothing about us without us” often is unheeded by academic researchers and public mental health systems. Accountability is woefully lacking in terms of meaningful consumer and family involvement in identifying needs; prioritizing

service development; developing treatment protocols and performance indicators; quality assurance; and the evaluation of recovery-oriented outcomes.

The National Research Project for the Development of Recovery Facilitating System Performance Indicators directly addresses the critical need to make the public mental health system more responsive to mental health consumers and make systems more consumer driven to improve accountability (New Freedom Commission on Mental Health, 2003). The National Research Project has developed appropriate structures and methods that consistently obtain and incorporate consumer perspectives into the assessment and evaluation of mental health services.

In summary, the National Research Project for the Development of Recovery Facilitating System Performance Indicators addresses the need to improve the recovery orientation of mental health care, the heightened demand for accountability to service recipients, and the need to attend to the consumer voice. The National Research Project has attempted to systematically learn from mental health consumers across the United States, create rigorous tools based on consumer perspectives, and develop methods for accountability that increase the impact of the consumer voice. The development of the ROSI performance measurement system is a step toward improving accountability to consumers and facilitating the potential for recovery. The ROSI tools were based on the experience of recovery as revealed by consumer/survivors. The intended audience for the tools includes mental health consumers as well as payers, providers, and mental health officials.

Part II. Overview of Phase I and Foundation for Phase II

While this report primarily details the work undertaken during Phase II of the National Research Project for the Development of Recovery Facilitating System Performance Indicators, the work builds on the foundation of Phase I efforts. This section summarizes Phase I.

Consumer representatives and staff of several State Mental Health Authorities (SMHAs) interested in measuring mental health recovery, staff from the National Association of State Mental Health Program Directors (NASMHPD) and the Center for Mental Health Services (CMHS), and recovery researchers (including several consumer researchers) gathered in May 2000. After reviewing recovery research efforts, the participants agreed that the existing instruments did not adequately measure recovery at the systems-level. In addition, they did not want to pull questions from instruments that had not been adequately psychometrically tested. Most important, the participants believed that the mental health field lacked an adequate basic understanding of the range of factors that advance or hold back personal recovery.

In a series of follow-up teleconferences, participants agreed on the need to conduct research that could inform the development of valid and reliable system-level recovery performance indicators. The National Research Project for the Development of Recovery Facilitating System Performance Indicators evolved, with a core Research Team (i.e., Onken, Dumont, Ridgway, Dornan, and Ralph) to lead and coordinate the work of the project. The Research Team worked with the 2000 meeting participants and with additional research partners (primarily SMHAs) and institutional sponsors to carry out the project. The five-member Research Team is primarily made up of researchers who are also on a personal journey of mental health recovery. Four of the five Team members have psychiatric diagnoses and several were prominent consumer researchers known for their work in mental health recovery.

To ground the development of system-level recovery indicators in lived experience, the Research Team designed a study (Phase I) that gathered qualitative data from people in recovery. Consensus among the Research Team and research partners established the importance of looking at mental health recovery broadly, as a transaction between an individual and his or her environment (ecologically) rather than concentrating on the impact that formal mental health services and systems have on recovery. Therefore, the Phase I study looked at a range of contextual, structural, interpersonal, and individual factors that tend to help or hinder the process of personal recovery. The Team focused the research on several dimensions identified as most important in brainstorming conducted at the original 2000 meeting. These dimensions were (1) resources/basic needs; (2) choices/self-determination; (3) independence/sovereignty; (4) interdependence/connectiveness; and (5) hope, as well as (6) how formal mental health services and programs specifically facilitate or impede personal recovery.

Description of the Phase I Study

The Phase I study was a multisite, multistate effort. Representatives of the SMHAs of nine states (Arizona, Colorado, New York, Rhode Island, Oklahoma, South Carolina, Texas, Utah, and Washington,) were active research partners in the effort. The Research Team selected focus group

research, because that method can generate a great deal of rich data in a short period of time and allows the collection of a broad range of ideas at a reasonable cost with efficiency of effort (Krueger & Casey, 2000). The SMHAs recruited participants using a purposive variability sampling strategy to involve a diverse group of participants and acquire a wide range of perspectives. The SMHAs hosted the focus groups. Trained facilitators conducted the groups using a uniform protocol developed by the Research Team that included guidelines on group process, informed consent, and a set of questions that were asked at all the sites. Ten focus groups were conducted in nine states.

Description of Focus Group Participants

Participants in the Phase I study were adults with serious and persistent psychiatric disorders. A total of 115 people participated in the 10 focus groups. The participants were predominantly female (58%) and of middle age (46% were 40–49 years old; 23% were age 50–59); a small proportion were younger or older. Most (69%) were white; 12% were African American; with the remaining number consisting of other racial or ethnic minority groups. Participants' education levels ranged widely—from high school or less (25%), to some college or technical training (35%), to college or technical degrees (30%) and graduate studies (20%). It was a fairly well-educated group. Participants' household monthly incomes were generally very low to modest: 8% were below \$500; 27% were \$500–\$999; 28% were \$1,000–\$2,000; and 13% were higher. Most participants were not married (42% were divorced or separated and 30% had never been married), although 53% had children. Almost three-quarters (73%) of the participants had been hospitalized for psychiatric reasons, and 84% said they had received a formal psychiatric diagnosis.

Analysis of the Qualitative Data

The focus groups were audiotaped and transcripts were prepared by the SMHAs. The transcripts averaged more than 100 pages and totaled more than 1,000 pages. Each transcript was analyzed by a member of the Research Team, using constant comparative methods (Glaser & Strauss, 1967; Lincoln & Guba, 1985). Brief reports were prepared summarizing the findings of each focus group. More than half of the original participants in the focus groups were recontacted in a process called “member checking” and were asked to verify the tentative findings, raise any concerns with the way the data had been summarized, and make suggestions for revisions. Participants were also asked to state their priority issues within each major theme to help the Research Team translate the extensive findings into a brief set of meaningful system-level indicators.

The Research Team achieved consensus on a comprehensive set of coding categories that summarized the major themes and findings across all the focus groups. Recovery was found to be a multifaceted process that can be facilitated or impeded through the dynamic interplay of many forces that are complex, synergistic, and linked. Recovery was synthesized as a product of dynamic interaction among the characteristics of the person (including the self/whole person, hope, a sense of meaning and purpose); characteristics of the environment (including basic material resources, social relationships, meaningful activities, peer support, formal services and staff); and characteristics of the exchange between the person and the social and physical environment (including hope, choice/empowerment, and independence/interdependence). Recovery is best

understood as occurring in an ecological framework as a process of transactions between the person and his or her environment.⁶

Research Team members selected exemplary quotations from the focus group participants to illustrate the major findings. A comprehensive report was prepared that describes the background of the study, study methods, findings, and implications. This report, *Phase I Research Report: A National Study of Consumer Perspectives on What Helps and Hinders Recovery* (Onken, Dumont, Ridgway, Dornan, & Ralph 2002), is widely requested and used in education, research, planning and advocacy efforts here and abroad.

The Research Team has used multiple dissemination strategies and venues to share the results of the Phase I research, as well as the progression of the Phase II work. Appendix A contains a list of dissemination activities.

⁶ To review a summary of the findings of the Phase I research, please see Endnote (4). The Phase I Research Report is available at <<http://www.nasmhpd.org/>>. Click on “publications,” scroll to “National Technical Assistance Center for State Mental Health Planning (NTAC) Publications and Reports,” scroll to and click on “Technical Reports” and the report and appendices are under the 2002 listing.

Part III. The Work of Phase II: Creating Recovery Performance Indicators

In this section we briefly discuss theories associated with the research approaches taken in Phase I and Phase II, then describe the steps we took in Phase II to develop system-level performance indicators on recovery.

Theoretical Context

There are many ways to look at how knowledge is developed in the social sciences. How the knowledge is developed, in turn, has an impact on how research and evaluation are carried out. One set of theories divides knowledge-making into two different kinds of knowledge, which correspond to two quite distinct concepts about generating knowledge. The first type of knowledge-making seeks to understand the complex interacting systems and processes that shape a given social circumstance, such as how people recover and how multiple influences may help or hinder recovery. This type of knowledge-making often calls for “critical/participative” approaches (Walker, 2002). The Phase I research was this type of knowledge-making activity.

Critical/participative research draws primarily on qualitative information that, after rigorous analysis, represents the social world as experienced by key participants. In this approach, knowledge is understood to be socially constructed and to typically reflect the interests of powerful groups. Critical research aims to empower disadvantaged groups by challenging dominant perspectives and attending to alternative perspectives, which can lead to new understanding that may be used to engender or promote social change. Such knowledge-making activities seek to bring to light underlying power dynamics that shape how services are provided and reveal the complex experience of service recipients.

The second set of approaches to knowledge-making corresponds broadly to traditional quantitative, empirical research. These approaches generally assume that there is a relatively straightforward linear relationship between service interventions and consumer outcomes. Research is seen as a value free way to produce clear information about the effectiveness of services (Walker, 2002). Research that fits into the positivist empirical category sets out to objectively measure the effectiveness of interventions in order to produce reliable evidence to inform policy and service development. The idea of finding objective ways to measure effectiveness fits well with the development of evidence-based practice and provides a means of holding mental health professionals to account through quality assurance, program audits, and other management practices. Outcome measures and performance indicators generally fit into this type of approach.

A serious shortcoming of quantitative empirical approaches and the associated research methods is their acknowledged inability to adequately reflect the complexity of people’s lives. Empirical measures attempt to simplify and quantify experience and to count experiences. They are designed to reflect group averages or tendencies, not to reflect an individual’s experience. Oversimplified measures of performance or progress can convey a distorted image of the effectiveness of service

systems and can lose the nuances and complexity that characterize each person's unique journey of recovery.

As the National Research Project moved from Phase I (understanding the lived experience of recovery and the complexity of the forces that formal helping systems have that help and hinder people in their process of personal recovery) to Phase II (the development of system-level recovery performance indicators), the Research Team faced the tension inherent in transitioning from a critical/participative qualitative approach to a quantitative, empirical approach.

David Howe's distinction between "surface" and "depth" in social service practice may provide a helpful way of thinking about this tension (Howe, 1996). The "depth" approach to practice is concerned with the professional working in partnership with the person to develop a more profound understanding of that person's strengths, needs, barriers, and opportunities in the context of the person's unique experiences, natural network, and larger social environment or community. How the complex interacting factors are constructed, understood, and managed in the context of a person's life should inform the selection and provision of services. Today's social service practice is often time-limited and task-centered. According to Howe (1996), this has caused a move to "surface" social service practice that has been characterized by a concern with *what* people do and with managing behavior rather than with *why* they do certain things. There is less emphasis today on trying to alleviate the underlying social situations that influence the person's problems. The actions of helpers are increasingly guided by policy and procedures rather than by knowledge of the social sciences, experiential practice wisdom, or professional expertise. Relationships with social service clients are often short-term and instrumental rather than being concerned with meaningful engagement and the possibility of deep personal and social change.

People's identified needs and their understanding of what help might offer them are often out of step with the way the service system has evolved (Walker, 2002). Social service professionals and consumers expect to function in ways consistent with depth practice, but they encounter a system that increasingly emphasizes a surface approach. As a result, it is common (as shown in the Phase I findings) that consumer/survivors feel a tension between what they know will help them achieve personal recovery and what mental health systems define as appropriate practice and effective use of the systems' resources.

Critical realism, which draws on the work of Bhaskar (1979, 2002) and Sayer (1992) may provide a helpful theoretical framework that can accommodate the interaction between the surface and depth approaches. Critical realism would say that it is possible to develop knowledge about what approaches are likely to be more or less effective in helping people achieve recovery, but that a determination of what constitutes "effectiveness" requires more than measurement based on the opinions of professionals or experts. In fact, effectiveness may be defined in different ways by different stakeholders. A critical realist perspective would say that the more valid definition of effectiveness would be that which conforms most closely with people's lived experience. Critical realism views the job of social research as developing an understanding of lived experience first to inform further research and evaluation. The Phase II process of developing performance indicators can be seen as proceeding in alignment with the theory and approach of critical realism by basing research and evaluation on the consumers' lived experience.

Development of Indicators for Prototype Test and Key Informant Review

In this subsection, we describe the preliminary steps taken in Phase II of the National Research Project to create recovery performance indicators based on the qualitative findings captured in Phase I. The steps included generating and refining items, seeking feedback, identifying data sources, selecting response scales, and formatting indicators. In the following subsections, we detail the further refinement and testing of prototype self-report recovery indicators, operationalization of the indicators, and securing key stakeholder feedback. In these steps, the Team moved from creation to testing and operationalization to the analysis of preliminary findings.

We discuss the specific steps in creating recovery-oriented system performance indicators and highlight the advantages as well as the limitations of the methods used. The end result is quantitative, empirical measures that are ready for large scale pilot testing and that will be valuable in assessing the recovery orientation of service systems while respecting the life experience of mental health consumers.

Generating a Large Pool of Performance Indicator Items

As a part of a five-day meeting in June 2002, the Research Team held a workshop to write performance indicator items. The Team based its brainstorming sessions on the 29-page coding category framework developed in Phase I and wrote items based on the Phase I codebook that was developed when the findings and themes from the focus group research were analyzed and summarized. All the coding categories (and, therefore, the structure used to develop performance indicators) were grounded in the lived (i.e., “depth”) experiences of consumers as they identified the factors that helped or hindered them on their recovery journeys. These categories are listed in the box below. As the Team revised, reconceptualized, refined, and simplified the items that could be used to quantify program performance (i.e., moved from the depth toward the surface of experience), they repeatedly found ways to regroup the work in the lived experience of consumer/survivors. The Team followed the general rules for brainstorming (Dunn, 1981): Team members generated as many statements as possible; there was no criticism of other people’s ideas; people could ask each other for clarification.

Domains and Themes in the Phase I Codebook	
Basic Material Resources	Self/Whole Person
Hope/Sense of Meaning and Purpose	Choice
Independence	Social Relationships
Meaningful Activities	Peer Support
Formal Services	Formal Service Staff

The Team initially generated 326 performance indicators. As Team members generated these items, they identified those that lent themselves to consumer/survivor responses (i.e., a consumer self-report format) and those that could best be answered through other sources of data (e.g., administrative data). Most of the indicators were initially classified as consumer self-report items.

The consumer self-report items were distributed across the Phase I research domains as follows: Basic Material Resources (20 items); Self/Whole Person (32 items); Hope/Sense of Meaning and Purpose (16 items); Social Relationships (20 items); Choice (8 items); Independence (10 items); Meaningful Activities (16 items); Peer Support (4 items); Formal Services (148 items); Formal Service Staff (15 items); and Global Satisfaction (1 item).

Thirty-six items were initially identified as lending themselves to administrative level data inquiries. These items would best be answered through data provided by the program directly and collected and analyzed at the agency, corporate, or authority level (regional or state mental health authority). The administrative items were distributed across the Phase I themes as follows: Basic Material Resources (3 items); Self/Whole Person (2 items); Hope/Sense of Meaning and Purpose (0); Social Relationships (2 items); Choice (0); Independence (3 items); Meaningful Activities (1 item); Peer Support (1 item); Formal Services (23 items); and Formal Service Staff (1 item).

In a coordinated process of individual and teleconference work, each Research Team member then identified the indicators that he or she believed could best assess the recovery orientation of a mental health program or system. This cut out many items that focused more on personal recovery (such as those under the theme of Hope/Sense of Meaning and Purpose) and increased the emphasis on factors in service environments that facilitate or hinder recovery. The importance ratings Team members gave to each item were tallied. An item could have as many as five points, i.e., rated as important by all five members of the Team, but the actual tally of importance ratings ranged from one to four points. The Team eliminated all items that had two or fewer points and continued to work with the items that had received three or more points.

The next task was to improve the way the items were worded and to select the best items among similar or redundant items. A few new indicators were generated as the Team clarified the items. In a few instances, items were revised to reflect the actual wording of focus group participants, as captured in the Phase I focus group transcripts.

Review of an Initial Subset of Indicator Items in a Consumer Workshop

In September 2002, two members of the Research Team presented a workshop at a large national conference, Alternatives, run by and for mental health consumers. They described the Phase I focus group research and asked the 45 workshop participants to answer a set of 15 survey questions. The participants responded using a “strongly agree” to “strongly disagree” Likert-style response scale. They were also asked to assign an importance rating from 1 to 10 to each of the questions, with 10 representing questions considered to be most important in evaluating the quality of mental health services.

Responses to the 15 items were broadly distributed; there did not seem to be a skew toward high ratings of services, a problem that is well documented in general satisfaction surveys (Campbell, 1998a). The mean importance rating of the 15 questions was between 7 and 8 on the 10-point scale. The workshop was highly interactive and provocative, and helped the Research Team fine-tune the indicator set.

The presenters then asked participants for general feedback. One major issue that emerged from the vocal group of participants was that their assessments and responses would vary greatly if they were evaluating the peer-run services they received as distinguished from those administered and provided by mental health professionals.

Refining and Reducing the Set of Indicators

The Research Team reorganized, revised, sorted, and prioritized a working set of 154 performance indicator items on the basis of teleconferences and the feedback at the Alternatives conference workshop. Eighty-six of the 154 items were self-report questions; they were distributed across the Phase I study domains as follows: Basic Material Resources (7); Self/Whole Person (18); Hope/Sense of Meaning and Purpose (4); Social Relationships (8); Choice (6); Independence (4); Meaningful Activities (3); Peer Support (6); Formal Services (26); and Formal Service Staff (4). Fifteen of the items were administrative indicators (2 under Choice, 3 under Independence, and 10 under Formal Services).

A 53-item set formed a services matrix. The Team looked at the 101 items that did not fall into the services matrix and cross-walked these items to the priorities set by focus group participants in the Phase I member check. (Phase I participants had been asked to identify the three most important themes under each of six guiding questions and then to say which themes should be given the greatest attention in efforts to strengthen or change the mental health system so that it supported personal recovery.) This effort helped focus the Phase II work of developing performance indicators that were relevant to, and valued highly by, consumers of services.

Meeting to Refine the Indicators and Reduce the Number of Indicators

The Research Team gathered in January 2003 for a five-day meeting to further refine and edit the recovery indicators. The Team used a process of consensus. The work involved rewording the prospective indicators, eliminating redundancies, and checking the items against the code categories of Phase I findings and consumer priorities and preferences as determined by the member check. Additional indicators/items were developed to ensure comprehensiveness. The Team reviewed several other current mental health system performance measurement efforts for ideas for its own editing and refining process.

The Team elected to include both positive and negative statements. The indicators, therefore, reflect the mental health systems' positive (helping) and negative (hindering) impacts on personal recovery. The recovery indicator set was edited for clarity, simplicity, and construct congruence. The Team retained items that best met all relevant criteria. This work resulted in the development of two sets of performance indicators: 69 indicators to be rated based on consumer self-report and 27 indicators to be gathered from administrative data.

In subsequent teleconferences, the Research Team reviewed the performance indicators one more time and added four self-report items. The item generation work concluded with 73 items based on consumer self-report data, laid out in a survey format, and 27 items based on administrative data.

Further Refinement of the Consumer Self-Report Indicator Set

In this subsection, we describe the response scale selection, think-aloud process, and prototype test of the 73-item self-report performance indicator set. We detail the results of the prototype test and review, and tell how these results were used to refine the self-report indicator set.

Selecting Response Scales for the Self-Report Survey

At the January 2003 meeting, the Team considered which response scales to use for the consumer self-report items. They reviewed the approaches used in various existing measures. One of the scales examined was the Mental Health Statistics Improvement Program (MHSIP) Adult Consumer Survey, which uses a five-point agree-disagree Likert scale that ranges from “strongly agree” to “neutral” to “strongly disagree” and includes a “not applicable” category. The Team examined the approach used in the Experience of Care and Health Outcomes (ECHO) survey,⁷ which uses screener yes/no questions followed by frequency scales. The Team also considered the approach used in the Recovery Measurement Tool (RMT), which uses a five-point scale ranging from “not at all like me” to “very much like me” and includes a “not applicable” category.

The Team narrowed its consideration to either an agree/disagree scale or a frequency scale. They deferred discussion of the use of screener questions until they could touch base with SMHA research partners. Some Team members believed that if the survey did not use screener questions, it should include a “does not apply to me” category for all self-report items. The Team agreed that regardless of the response scale, the response categories would be arranged from “disagree” to “agree” or from “never” to “always.” The Team’s experience was that such ordering can help discourage overselection of positive responses, a response bias that makes most consumer satisfaction surveys relatively useless for purposes of system change.

Having narrowed the choice to either an agree-disagree scale or a frequency scale, the Team generated a list of potential strengths (e.g., the states were familiar with the MHSIP agree-disagree scale) and weaknesses (e.g., respondents have difficulty with an agree-disagree response option if an item applies to more than one staff member or service). The Team developed several versions of each of the response scales, ranging from a four-point to five-point agree-disagree scale and a four-point to six-point frequency scale. They decided not to include a “neutral” response option. In qualitative work conducted by some Team members, respondents had been found to select that category when they were indecisive, when they considered an item to be of little relevance or importance, when the item did not apply to them (even when a separate N/A category existed), or when their experience was mixed. For example, people might use a neutral response to answer a question such as “Staff were willing to see me as often as I needed” if it held true for their caseworker but not for their nurse.

⁷ The Experience of Care and Health Outcomes (ECHO) survey is designed to collect consumers’ ratings of their behavioral health treatment. The ECHO contains items that assess consumer experience with specialty behavioral health care, including mental health services and alcohol, drug, and other substance abuse services.

The Team agreed to select the response option that best fit each question/item and that could most easily be interpreted. They reviewed each self-report item and applied both the agree-disagree and the frequency response scales to the item, then selected the response scale that seemed most appropriate. Slightly more than half of the items clearly lent themselves to a frequency response, while the agree-disagree scale was a better fit for the remainder of the items.

After consulting with some of the participating SMHAs, the Team dropped the idea of using screener questions. Most states were conducting surveys using a paper and pencil approach; they found that the skip sequencing required by screener questions generated confusion and inaccuracy. After consulting with several statisticians and survey researchers, the Research Team decided on the wording for the two response scales. They devised a four-point agree-disagree response scale consisting of “strongly disagree,” “disagree,” “agree,” and “strongly agree”; and a six-point frequency scale consisting of “never,” “rarely,” “sometimes,” “often,” “almost always,” and “always.” A “does not apply to me” category was included for all the self-report items. It was initially thought that people would avoid the “never” and “always” categories, but subsequent testing proved otherwise.

The Think-Aloud

The Research Team conducted a think-aloud to test the self-report indicator set with consumer respondents to further refine the items and improve the survey. A think-aloud is a process whereby a group of prospective respondents or research subjects share their thinking about particular content, especially survey questions. The think-aloud process has been used for several decades (Belson, 1968, in Sudman, Bradburn, & Schwarz, 1996). Think-aloud methods came out of the field of cognitive psychology as that field developed and overlapped with the field of survey research. The process is based on theoretical perspectives that have been advanced about the underlying cognitive processes involved when a person answers survey questions. People commonly undertake four tasks when they respond to survey questions (Strack & Martin, 1987, in Johnson, O'Rourke, Chavez, Sudman, Warnecke, & Horm, 1996): (1) they interpret the question; (2) they retrieve memories; (3) they form judgments; and (4) they edit their response. Attention can be paid to each of these tasks during a think-aloud.

In the project's think-aloud, most attention was paid to how people interpreted the questions. Sudman, Bradburn, and Schwarz (1996) point out that much attention in questionnaire development today is given to determining, through retrospective protocols, what the respondent thinks the survey question means. The authors suggest that this is the case because “understanding what a question is attempting to discover is the first stage in the respondent's cognitive answering process” (p. 17).

Respondents often interpret survey questions differently; the differences can be subtle or not so subtle. When people attribute multiple meanings to the same question or survey item, it reduces the likelihood that the research will validly measure what the developers intend it to measure. The process of having respondents share their interpretations by literally “thinking aloud” about each of the items on a survey can help those constructing a measure to refine their item set. By conducting a think-aloud before finalizing an instrument, authors can increase the likelihood that

subsequent respondents will arrive at similar interpretations and understandings of items, thereby improving the construct validity of the measure and the accuracy of survey results.

The Think-Aloud Process

Organized by the research partners from the South Carolina Mental Health Authority, the think-aloud was held in Columbia, South Carolina, in February 2003. A Research Team member facilitated the process. The 10 volunteer consumers recruited by the SMHA were given \$20 honoraria after the session to honor their contribution. After an introductory exercise and completion of a sheet that collected background demographic data, each participant received the 73-item question set formatted as a survey. Each participant read the same item and answered the question using the response scale provided. The facilitator then asked, "In your own words, what do you think this question means?" Respondents were given an opportunity to share their thinking about each of the items in sequence. Follow-up questions were asked. The facilitator and a recorder noted participants' verbal responses, including multiple understandings and disagreements as to the meaning of a given question or item. Some participants also wrote comments on their survey forms, which were collected as part of the think-aloud data.

All 10 participants shared their responses for most questions. Multiple meanings, discrepancies, or clarifications were noted for more than two-thirds of the questions (50 of the 73 items). Over the course of the day, participants shared general concerns about the survey instrument, including whether there would be open-ended questions and the suggestion that the survey ask about the length of time respondents had been receiving mental health services (e.g., less than three months, three to six months). As the day wore on, there was a slight departure from this protocol. In some instances, when all participants indicated that a question was clear and understandable, further discussion was forgone. All in all, the think-aloud discussion was active, lively, and very helpful. Several examples of responses to the survey questions are given below.

Q. I have work opportunities that are meaningful to me.

The word "work" was interpreted to include volunteer or paid labor, and both part-time and full-time work.

Q. I have opportunities to advance my education.

This was followed by a probe: "When you said that you had opportunities to advance your education, were you thinking of opportunities available on your own or through mental health staff/services?" Not everyone thought the question referred to opportunities available on your own and through mental health services. A few people thought that the question about advancing one's education should be qualified by the statement "if I want to."

Q. There was a peer advocate to turn to when I needed one.

Several people in the think-aloud were unfamiliar with the term "peer advocate." Some people understood "peer" but not "advocate"; some understood "advocate" but not "peer advocate." All respondents were familiar with the term "consumer."

Q. There was too much turnover in my mental health providers.

This was followed by a probe: “Do you feel this is a question that people would or would not have difficulty understanding?” Several respondents questioned whether other people would know what “staff turnover” is. Suggestions were made to use simpler terms, such as “I’ve had too many changes in providers” or “I’ve had too many different providers.”

Q. Mental health staff support my self-care or wellness.

Several respondents thought it was not clear whether “wellness” referred to both physical and emotional wellness.

Through teleconferences, the Research Team modified the wording of several of the self-report indicators on the basis of the think-aloud feedback. For example, the phrase “if I want to” was added to the question about advancing one’s education. The word “consumer” was added to the peer advocate question. Definitions for peer services and integrated dual disorders treatment were written and were provided along with the directions for administering the survey. While numerous changes were made using the think-aloud results, suggested changes were not made in every instance. For example, there was discussion about the word “housing,” and some respondents thought a better choice of words would be “a place to live.” The Team replaced the word “housing” with “a place to live” in one question but continued to use the word housing in another question. Similarly, participants suggested that the word “home” can have a bad association for some people. They suggested that the survey say, “I have a place to live that feels comfortable to me” and leave out the word “home.” The Team decided to add “feel comfortable” but chose to keep the word “home” in the question.

The think-aloud provided a lot of helpful information; however, the procedure had some limitations. More information probably would have been obtained from each participant if they had been interviewed separately rather than as a group. Individual interviews would have avoided group process effects such as the reluctance of a respondent to differ with the rest of the group; however, this effect seems to have been minimal, as participants in the think-aloud did express many differences of opinion.

As described, the think-aloud took an entire day. Additional structured questions could have been employed to more fully explore the range of cognitive processes involved in answering the survey questions. Such a process would have required more time and facilitator preparation, and thus would have been more costly. In the one-day session, the Research Team learned much about how respondents interpreted each question and relatively little about how they retrieved information from memory and formed their judgments, or about the cognitive processes that took place as they thought through and edited their responses.

Finally, much has been written about social or cultural distance and the inclination of some respondents to edit their answers depending on the perceived similarity between the interviewer and the respondent (Sudman & Bradburn, 1974, in Johnson, Sudman, Warnecke, & Horm, 1996). Given that the facilitator was also a consumer of mental health services, it is likely that respondents perceived this as a shared characteristic. However, the facilitator was a white female, and participants included several males and African Americans. It may be that cultural distance

played some part in the extent to which some respondents edited their answers or shared their thinking. In ideal circumstances, group facilitators and interviewers would more closely mirror the demographic characteristics of participants, including their race or ethnic status.

Seeking Feedback from SMHAs about Self-Report Items

The Research Team sought item-by-item feedback from participating SMHAs on the consumer self-report survey questions, and staff from two states responded. The Team reviewed the staff feedback along with the think-aloud feedback and refined the items as warranted.

Assessing the Reading Level of the Self-Report Indicators

After the Research Team refined the self-report items on the basis of the think-aloud and SMHA feedback, the Oklahoma SMHA applied the Flesch-Kincaid Grade Level test item-by-item and developed a side-by-side chart. The chart listed the item on the left side with its current reading level and a suggested revision on the right side to reduce the reading level required of respondents. The original 73 self-report indicators used in the think-aloud session had a 7.1 mean reading level, while individual items ranged from 0.8 to 12.0 (i.e., high school senior). The Research Team reviewed the chart and further refined some of the items. The refined set of 73 self-report items was then developed into a survey prototype with an overall 6.1 mean reading level and a 1.0 minimum and 12.0 maximum reading level for individual items. Specific examples of the refinement effort are reflected in Table 2; for the full side-by-side comparison, see Appendix B.

Table 2: Reading Level Revision Examples

Think-Aloud Item Set	Refined Item Set
I have work opportunities that are meaningful to me.	I have paid work opportunities that are meaningful to me.
Mental health services provided the assistance I needed in obtaining a livable income.	Mental health services helped me obtain enough income to live on.
I was provided full information in language I understood before I consented to treatment (including medication).	Staff give me complete information in words I understand before I consent to treatment or medication.
Mental health services interfered with my personal relationships.	Mental health staff interfere with my personal relationships.
I had access to medications that worked best for me.	The doctor worked with me to get on medications that were most helpful for me.
I was not free to associate with people of my choice.	Service programs restrict my freedom to associate with people of my choice.
The mental health staff ignored my physical health.	The mental health staff ignore my physical health.
My mental health services created dependence, not independence.	Mental health services led me to be more dependent, not independent.

The Flesch-Kincaid Reading Ease/Grade Level Test has been around for 50 years; it is used to analyze a sample of writing to determine the grade level of the reading skills needed to understand the material. The tool examines the number of words, syllables, and sentences in a section of text. The Flesch-Kincaid tool is widely known and used and is included in the Microsoft Word and Word Perfect word processing programs. While the tool is based on proven research, like all readability programs, it must be considered as a guideline or reference point.

Testing a Prototype of the Self-Report Survey

The project used a design-prototype-test cycle to determine how well the draft survey functioned in the field, then used the findings from the field test to further refine the instrument. Prototyping is an essential element of an iterative design approach, in which designs are created, evaluated, and refined until a desired level of performance or usability is achieved. In the design-prototype-test cycle, the measure (or any other product) that is being designed undergoes successive mock-ups that are evaluated through some type of user testing, user feedback, or inspection technique. The cycle involves concept development and design, model development (resulting in a prototype), testing and evaluation of the prototype, and revision of the measure or other product, using the information gathered in the evaluation to improve the model or process.

The project prototype test assessed a mock-up draft of the 73-item Recovery Oriented System Indicators (ROSI) Self-Report Survey to see how well the measure would work under real-world conditions. The field test involved only the consumer self-report survey portion of the ROSI package. It did not include the administrative-based performance indicators (which were assessed in another set of procedures described later in this report). The Research Team worked with several SMHAs to test the prototype of the self-report survey to see how it functioned. The data were analyzed and the statistical findings were used to reduce the total number of items to make the ROSI more usable.

The 73-item draft ROSI self-report instrument was mocked up in a new format before it was given to SMHAs for the prototype test. The content was broken down into five sections. The first four sections alternated between the frequency and the agree/disagree response scales. Directions were created for the survey. Participants were asked to circle the *one* response that best represented their situation in general during the past six months. A fifth section was created to provide space for written comments and the answer to an open-ended question: “Are there other issues related to how services help or hinder your recovery? Please explain.” The survey was also formatted to gather respondents’ ratings of the importance of each item. Participants were instructed to assign an importance rating to each recovery performance indicator in the first four sections, with 1 signifying “of no importance” and 10 signifying that the item was “of the highest importance” in the evaluation of mental health services. Participants were further instructed to circle any word or phrase in the survey that was not clear. Participants were also asked to complete a brief demographic background sheet that had been adapted from the Phase I research. The sheet gathered data on 15 items concerning the respondent’s personal attributes and mental health history. Survey administrators were asked to use a unique code that would allow the Research Team to link the background sheet to the survey data completed by each participant.

The states participating in the prototype test agreed to get completed surveys from a purposive sample of at least 25 mental health consumers. The Research Team encouraged the SMHAs to proactively target and attempt to involve consumers who are often underrepresented (e.g., people who are homeless, people with dual diagnosis, young people, and people from minority populations). To accomplish this, states were encouraged to administer the prototype measure in several settings (e.g., at a homeless outreach program and at a substance abuse and mental illness dual treatment program).

Participation in the survey was voluntary. States provided small amounts of money or gift certificates as incentives to reward participation. Each agency followed established policies and procedures in its state for research and evaluation activities. Some states' policies required SMHA staff to submit materials to the Institutional Review Board (IRB) for review and approval to proceed. Because all data were de-identified and were only to be analyzed in the aggregate, most IRBs expedited the review process and waived formal review.

An Institutional Review Board (IRB) is the formal body that must review and approve all proposed research with regard to its impact on human subjects, in order to ensure that the research is undertaken ethically and the rights of participants are protected, including their right to full information, to agree or refuse to participate, and to be protected from exploitation or other risks.

Each SMHA had a trained staff member (in some cases, a consumer interviewer) administer the survey. The administrator followed a specified protocol that included providing participants with a written set of definitions devised by each state that explained and defined what services and which staff the respondents were evaluating, and defined any terms used in that state's mental health service delivery system. For example, the definitions explained what was meant by the word "program" and how that state defines "mental health services." In some instances, people were told to rate only services delivered directly by their local mental health agency or to include services that they receive that are contracted through, but not directly provided by, a local mental health agency. The definitions helped the person administering the survey answer participants' questions.

Some states administered the survey as a personal interview; others administered it to a group of consumers at a program site; and still others used a combination of these approaches. All locations followed informed consent procedures. The administrator began by walking the participant(s) through the first survey item. This allowed the administrator to explain the three separate steps the respondent had to take to answer each item (respond to the item, rate the importance of the item, and circle any unclear words or phrases).

"Informed consent" is the process by which researchers fully disclose any known risks or potential benefits to those participating in the proposed investigation and provide information as to their rights as research participants, including the right to withdraw from the research at any time. The signature of the participant or his or her legal representative is often requested to document that the person understands his or her rights and voluntarily grants his or her consent.

Those administering the ROSI were asked to review each survey as it was completed, to check for missing data and, if possible, to ask the participant if he or she had accidentally or intentionally skipped the question. The survey administrator encouraged the person to complete any missing data or record the reason he or she chose to skip the question. Finally, the person administering the survey completed a brief report that described how the survey was administered, the results of the review of the completed surveys, and any variations in the process (e.g., the involvement of a translator).

Seven SMHAs (Arizona, Colorado, Hawaii, Oklahoma, Rhode Island, South Carolina, and Texas) tested the ROSI self-report prototype. The number of completed surveys ranged from 25 to 40 in each state, for a total of 219 completed surveys.

Managing and Analyzing the Data from the Prototype Test

The Human Services Research Institute (HSRI) of Cambridge, MA agreed to enter and manage the data set from the multisite prototype test of the ROSI self-report questionnaire. Each SMHA kept a data set and submitted a copy of the data to HSRI. The Hawaii site took the lead by creating a codebook and a statistical package for the social sciences (SPSS) spreadsheet for its data set. HSRI adopted this codebook and used the Hawaii spreadsheet as its master data entry file. Hawaii and Oklahoma submitted their data electronically using the spreadsheet. Data from all other surveys were hand entered at HSRI.

In a teleconference with the Research Team, HSRI expanded the codebook to cover all sites and addressed all data inconsistencies and unclear responses. The final multisite Phase II codebook included general coding rules and specific rules related to demographic items, self-report items, and response scales. An example of a general rule was “If respondent does not check any boxes but instead writes a comment that is illegible, nonsensical, or does not answer the question as asked, code data as uninterpretable.” Examples of response scale rules include “If 2 responses are circled, use the alternating high-low method of coding” and “If item is rated 0, code as 1 (lowest).” Because the Hawaii and Oklahoma data had been submitted electronically before the multisite codebook was finalized, a Research Team member reviewed the hard copies of the Hawaii and Oklahoma surveys against the electronic files to revise any entries that did not follow the rules established in the codebook.

The Center for Information Technology and Evaluation Research at the New York State Office of Mental Health (NYSOMH) conducted the initial data analyses requested by the Research Team. HSRI supplied two files, one with the data entered as is and one that reverse-coded the responses to the negatively worded items. Three of the Research Team members spent four days at NYSOMH in November 2003, developing initial data runs and interpreting the data. Research Team members subsequently conducted further analyses of these data using both SPSS and Stata statistical software.

Prototype Test Respondent Demographics

Two hundred and nineteen people completed the prototype of the ROSI Self-Report Survey. These mental health consumers first answered 15 questions about themselves and their mental health condition. This section summarizes these demographic data. The percentages below do not include

missing data. Graphs of the full findings on the participant demographics can be found in Appendix C.

The majority of the participants in the prototype survey test were female (58%). Participants were predominantly of middle age, 30–59 years (87%), with only 8% between the ages of 18 and 29 years and slightly less than 5% age 60 years or older. Multiple entries were allowed in reporting race and ethnicity: 72% of the respondents identified themselves as white; 13% as African American/Black; 12% as Asian American; 6% as Native American/American Indian; 6% as Native Hawaiian/Other Pacific Islander; and 6% as “other.” In another question, 10% said they considered themselves Hispanic or Latino/a.

Only 15% of the respondents were married; 38% were divorced; 36% were single/never married; and nearly 10% responded “other.” Slightly more than half of respondents were parents (53%), while 46% were not. More of the participants reported that they lived alone (37%), while 18% lived with a spouse or significant other, 13% lived with family, 12% lived in a supervised facility or boarding house, and 15% were homeless. The majority of the participants lived in urban areas (64%); 28% lived in a suburban area; and less than 6% lived in a rural area. Many participants reported low monthly incomes of \$500–\$999 (40%) or less than \$499 (29%); 19% had an income between \$1000 and \$1999; and only 6% had \$2000 or more in monthly income.

Participants reported a wide range of educational backgrounds, with the highest percentage reporting “some college” (37%); 32% were high school graduates or GED (General Education Diploma) holders; and 21% were college or technical school graduates. Twelve percent had less than a high school education, while 7% had completed graduate school, 2% had “some graduate school,” and slightly less than 6% responded with “other.”

Multiple entries were allowed in reporting psychiatric diagnoses. Mood disorders predominated: 42% of participants reported experiencing bipolar disorder and 40% had depressive disorder. Twenty-one percent of participants reported experiencing posttraumatic stress disorder (PTSD); 16 percent, schizophrenia; 16 percent, schizoaffective disorder; and 20 percent, other diagnoses. A large majority—80% of participants—agreed with their psychiatric diagnoses, although nearly 10% disagreed. In terms of drug and alcohol addictions, 48% had been diagnosed with an addiction. Participants reported on their current mental health status: 27% reported excellent/very good overall mental health; 34 percent, good; 31 percent, fair; and 7 percent, poor/very poor.

Most of the participants had been hospitalized for psychiatric reasons (78%). Among those, 11% had been hospitalized once; 37% between two and five times; 17% between 6 and 10 times; and 11% more than 10 times. Participants reported the total length of time they had used mental health services: 51% reported five years or more; 14% reported two to five years; 9 percent, 13–24 months; slightly less than 6 percent, 7–12 months; and 11 percent, less than 6 months. Less than half of the participants (44%) had been involved in consumer/survivor organizations.

Comparison of Phase I and Phase II Respondents

The demographics of participants in Phase I (focus group participants) differed somewhat from those in Phase II (prototype test participants). There were 219 participants in Phase II compared

with 115 in Phase I. Other prominent differences are the 33 homeless participants in Phase II compared with 1 homeless person in Phase I; the percentage of Phase II participants diagnosed with a drug or alcohol addiction (48%) compared with Phase I (25%); and the number of participants in Phase I who had participated in a consumer/survivor organization (75%) compared with Phase II (44%). Another difference is that 69% of Phase II participants report less than a \$1,000 of month income compared to 35% of Phase I. Demographics are remarkably similar in terms of gender, age, and race/ethnicity, with both Phase I and Phase II having a slightly higher percentage of females, ages concentrated between 30 and 59 years, and a majority of white participants. Other similarity is that slightly more than half with children. Psychiatric diagnoses are similarly distributed as well, with a majority of mood disorders (72% in Phase I; 81% in Phase II), followed by PTSD, schizophrenia, and schizoaffective disorders.

Indicator-Related Data from the Self-Report Prototype Survey

This subsection provides selected findings of the initial multisite field test of the consumer self-report survey, along with a short commentary on the prototyping effort in general. Responses are aggregated for each survey item and displayed in bar graphs in Appendix D.

The prototype 73-item ROSI Self-Report Survey performed well, in general. There was little missing information, indicating that respondents could answer the questions. Few people skipped over questions or left parts of the survey blank. People did use the category “does not apply to me,” but its use varied across the 73 items. The Research Team knew that some questions were universal and would apply to most people, while others would apply to only a portion or subpopulation of service recipients.

There was quite a bit of variation in how people answered the 73 questions. Those completing the survey did not simply select a particular response and keep answering the survey that way; instead, they varied their responses from question to question depending on the content of the question. Responses differed across the group of respondents as well as within a given person’s survey. The variance in the way people responded to the survey shows that the system-level indicators of recovery were not answered as if they were part of a typical general satisfaction survey. Findings of consumer satisfaction surveys commonly show a predominant pattern of highly positive responses (e.g., people generally say they are satisfied or highly satisfied with the services they receive). Because people have a hard time expressing dissatisfaction with the services they receive, general satisfaction surveys have a positive bias that is not helpful in efforts aimed at improving the quality of services or the performance of programs.

In general, research findings should show sufficient variability in the patterns of answers in order for the findings to be interesting and the survey to be sound. The variety of responses means that the ROSI Self-Report Survey data can be used to identify areas in program performance where change is needed and those where recovery promoting practices are already in place. The variability in response also can allow researchers to make comparisons across programs, because people aren’t rating all components of programs or all performance indicators in a system in a uniform way.

Respondents in the prototype survey were able to answer questions about both positive (recovery enhancing) and negative (recovery hindering) experiences and practices in their local system. They were able to shift between the two types of questions without seeming to mix up their responses, a problem identified in earlier survey research efforts.

Summary and Highlights of the Findings

This subsection describes highlights of the general findings for all the respondents on the prototype survey.

The recovery hindering factor of insufficient basic resources for a decent quality of life is exemplified by one question on the survey that concerned income. Nearly 60% (59.4%) of respondents said they strongly disagreed or disagreed that they had enough income to live on.

Having meaningful activities, including employment opportunities, is important to promote recovery, and jobs give people income and a positive source of identity, along with a potential social network. Yet, nearly half the survey respondents (46.5%) said they never or rarely had access to work opportunities that were meaningful to them.

The survey includes items that test whether staff believe recovery is possible, because the focus group findings emphatically indicated that staff who do not believe in the potential for recovery hinder the consumers' potential to recover. Data from the prototype field test show that more than half (56.3%) of respondents said that staff almost always or always believe that they can learn, grow, and recover. While this finding suggests that a large proportion of staff seem to embrace the concept that people have the potential to grow and recover, a considerable proportion of staff still do not know about or support recovery.

Being treated as a whole person facilitates recovery, while being viewed largely or exclusively in terms of one's problems, symptoms, psychiatric label, or stigmatized identity hinders recovery. In the prototype survey, more than half of the respondents (53.4%) said they almost always or always are treated as a psychiatric label rather than as a person in their mental health program. Part of the whole person perspective is being seen and treated in a holistic manner that includes aspects of one's physical, emotional, intellectual, social, and spiritual well-being. Despite the need for such a perspective, nearly two-thirds of the respondents (63.5%) agreed or strongly agreed with the statement that mental health staff ignore their physical health.

The mental health system should aim to increase well-being, and a core aspect of helping is to first do no harm. A surprisingly high proportion of the respondents—nearly two out of three (63%)—said that mental health services had caused them emotional or physical harm.

Many people in the Phase I focus groups that led to the development of the prototype self-report survey said that staff control and forced treatment hindered their personal recovery. The pervasive use of force in mental health service systems was clearly shown in the data from the Phase II field test of the prototype survey. All but 2.5% of the respondents had experienced forced treatment or forced medication at some point: 14.2% experienced forced treatment often; another 10% experienced it almost always, and fully 59.8% said they always experienced forced treatment.

Data from Phase I of the National Research Project indicated that staff can hinder recovery by taking over many aspects of the person's life and making too many decisions for the person. Data from the Phase II prototype survey show that most respondents said staff often (13.7%), almost always (15.1%), or always (47%) interfere with the respondents' personal relationships.

Ready access to high quality, effective mental health services is a hallmark of a recovery-oriented system, and many systems are targeting the development of best practice services in areas such as supported employment, illness self-management, and integrated dual diagnosis treatment. Yet, almost three out of four respondents (71.7%) believe that staff often, almost always, or always lack up-to-date knowledge of the most effective treatment. More than half of the respondents (55.2%) said they could not get the services they need when they need them, indicating a problem with access to services and lack of availability of appropriate help that could facilitate recovery.

A high proportion of respondents either agreed (36.5%) or strongly agreed (20.5%) that they lack the information or resources they need to uphold their client rights and their basic human rights.

Other data show a more positive aspect of the recovery orientation of the service system. Nearly half the respondents (47.1%) said they always or almost always have a say in what happens to them when they are in crisis. In the past, people seldom were able to influence what happened during a crisis.

In Phase I, many participants described peer support as the most important resource in promoting their personal recovery. In the Phase II prototype test, most respondents (71.2%) agreed or strongly agreed that they were encouraged to use consumer-run programs, such as support groups and drop-in centers.

Self-responsibility, a sense of self-agency, and the self-management of one's life and psychiatric condition are hallmarks of mental health recovery. Most respondents agree (47%) or strongly agree (31.5%) that staff encourage them to take responsibility for how they live their life.

Overall, the findings from the field test of the 73-item survey show a mixed picture of local mental health systems that both hinder and promote recovery. These initial findings reveal a great need for further evolution toward a recovery orientation in mental health systems.

Content Analysis of Participant Comments on the Self-Report Prototype Survey

Participants were asked, "Are there other issues related to how services help or hinder your recovery? Please explain." Of the 219 participants, 113 offered written comments. Comments included observations of negative aspects of services (36); reports of stigma experienced in treatment (11) and in the wider society (3); internalized stigma (1); budget limitations in the service system (5); and positive experiences with services (31). Participants offered recommendations for improving services (23) as well as comments and reflections on the survey design (15).

Participants expressed many concerns about the quality of mental health services. One wrote, “It’s like band-aids on severed arms. No actual therapy takes place. They simply throw medications at us, that I am convinced simply repress the problems.” Five respondents commented on the inconsistency of services, particularly psychiatric services, and identified “having to see a new doctor every time I go to the clinic” as an obstacle to recovery. Five others reported that the quality of case management services is mitigated by case managers’ lack of experience, lack of education and training, and crowded schedules. Participants identified specific gaps in services, including a lack of child care opportunities for parents, lack of access to affordable medication and affordable housing, lack of information about available services, and a one- to two-month backlog in services. Other comments included one that detailed a breach in confidentiality, another recounting an experience of cruel treatment in a psychiatric hospital, and another on the need for consumers to “push and seek or stumble on the thing or person who can help. Not all clients have that force within themselves, and are left behind.”

Some who reported having experienced stigma in treatment described the treatment setting as “cold and unfriendly” and indicated that “I am viewed as a ‘mental patient’ at the clinic, and I am, but if I went to a doctor as a ‘kidney patient’ I would not be treated with coldness and stigma as occurs because of my particular illness.” Another drew a link between doctors’ lack of hopefulness and their own recovery, stating that “I know recovery is possible and it hinders me 101% to have a doctor tell me I’ll never get better.” Three participants described stigma that they had experienced in the wider society, specifically at the Department of Motor Vehicles, employment agencies, and in education settings. One participant reported that “self-stigma plays a big part in keeping me isolated and not part of the larger community.”

Positive comments about services included reports of good referrals for housing, employment, and dual diagnosis services, as well as positive experiences with finding the most effective medication and having a supportive relationship with a therapist, psychiatrist, or case manager. Consumer/survivor groups and support groups were named as pivotal in supporting recovery. One participant attributed recovery to supportive services, stating that “staff has been the major factor in my recovery”; while six respondents named specific staff or entire agencies that had been helpful.

Recommendations for increasing the breadth of services included a call to expand services to hire consumers and use their skills, two comments about drawing family members into the treatment setting, and two comments about increasing the number of self-help support groups. The referral process could be improved by creating a governing agency to regulate it, and no one should be told, “I’m sorry, we can’t help you.” Two participants identified a need for better coordination of care between prescribing doctors and pharmacists and between mental health services and other government services, while two others called for realistic and self-directed treatment plans. Some respondents wanted more holistic care, including two participants who want to have homeopathic treatment approaches included in services and another who identified Tai Chi as a means to recovery. Other comments highlighted the need for more opportunities for community inclusion and the need to educate “normal” people about mental illness.

The 15 comments about the survey itself included identification of confusing elements (for example, the importance ratings being placed after the participant's own response to the item) as well as specific items that were confusing or vaguely worded.

Factor Analysis of the Prototype Test Data

A factor analysis was conducted on the survey data, primarily for data reduction purposes. The results served as one input to the decision-making process about which items to delete to achieve a shorter and tighter self-report survey.

Factor analysis refers to a variety of statistical techniques that attempt to represent a set of variables in terms of a smaller number of underlying variables or factors. In basic terms, the steps of factor analysis involve the formation of a correlation matrix, extraction of the factors, and rotation to a terminal or “best fit” solution that reduces the variables into a set of factors that are related to one another mathematically.

Factor analysis is usually approached either as “exploratory” or “confirmatory.” The Research Team approached the factor analysis as exploratory, which means that there was no attempt to prespecify the number of factors and their loadings. They took this approach because of the modest sample size and because they recognized that there were potential interrelationships among the items that would likely differ from the conceptual scheme or set of research domains that had been identified in Phase I.

A subgroup of the Research Team conducted the factor analysis with the technical support of the New York SMHA. The Team relied on principal component analysis as the extraction method and used Varimax rotation with Kaiser normalization as the rotation method. These methods were applied to the complete set of 73 items. The factor analysis of the 73 items resulted in an eight factor solution. All eight factors had eigen values above 1; together, they accounted for 100% of the variance. It was good that the solution rendered a substantial number of factors, particularly given the modest sample size (N=219).

After examining the items according to factor to see whether conceptual sense could be made of the components, the Team examined the factor loadings for each item. The factor loadings are a coefficient in a factor pattern. The Team used the factor loading values as one input into the decision of whether to retain or delete a given item. The higher the factor loading, the more likely it was that the item was retained, although this was not applied as a strict rule.

A consulting statistician pointed out that factor analysis is both science and art; most books tell you about the science, while the art part is hardest (S. M. Banks, personal communication, February 9, 2004). Using multiple criteria described below, the Team reduced the questionnaire to 41 items. These items were reviewed by the full Research Team, with opportunities to reconsider any item that had been dropped. The end result was a 42-item questionnaire. The Team ran another factor analysis on the 42 items, interpreted the factor solution, and tentatively named the factors.

The Research Team considered relatively high factor loading values in deciding whether to retain or delete an item. In the process of developing scales, it is common practice to retain items with factor loading values of .5 or higher. Because all the self-report items loaded on at least one factor at .5 or higher, this criterion was not helpful for deleting any of the items. Thus, the Team considered a relatively high factor loading value to be .7 and above. Analysis revealed that 71% of the items (52) were in the range of .7 and above. A reanalysis conducted after the multiple criteria deletion strategy was used showed that 79% (33 of 42) of the items retained had factor loadings of .7 or above. Of the items deleted, 39% (12 of 31) had factor loadings less than .7 but greater than .5.

The factor analysis conducted on the reduced 42-item self-report question set resulted in an 11 factor solution. These 11 factors all had eigen values above 1 and together accounted for 78% of the variance. The Team combined the factors into eight components and named them in an interpretive process. (The items corresponding to each of the factors are listed later in this report.) The fact that a substantial number of factors were obtained with a relatively small sample is positive. That a similar number of factors were found in the reduced item set compared with the 73-item set suggests that the underlying factor structure was preserved even as many of the items were deleted. Although promising, the results of the factor analysis should be viewed as tentative because of the small size of the sample relative to the large number of questions on the survey instrument. In addition we do not know how responding to the 73-item set might differ from responding only to the reduced 42-item set and how this potential difference might affect the factor analysis that results. The factor structure of the proposed 42-item questionnaire will be examined further in large scale field tests in Phase III of the project.

Importance Ratings: Procedures and Results

Respondents were asked to rate how important each item was for evaluating the mental health system, on a scale that ranged from 1 to 10, where 1 meant the item was of no importance and 10 meant that it was of the highest importance. This subsection describes and discusses the findings on importance ratings data.

Importance ratings were attained from 216 of the 219 respondents. In 65% of the items, 5% or less of the respondents chose not to rate the item; in 97% of the items, 10% or less chose not to rate the items. A few items were not rated by a larger percentage of respondents. For example, item #62, "Complaints or grievances about mental health services were respectfully resolved," was not rated by 24 persons (11% of respondents), and item #55, "I receive support to parent my children," was not rated by 55 persons (25% of respondents). Fully 67% of respondents selected "does not apply to me" for item #55 rather than indicating the extent to which they disagreed or agreed with the statement. This means that some respondents chose to rate the importance of the item for evaluating mental health systems, even though the item did not apply to them; 83% of people with children and 66% of those without children rated the importance of the question.

Respondents used both the lowest value of 1 and the highest value of 10 in rating the 73 items. The mean or arithmetic average of all ratings was obtained for each item (the sum of the rating values divided by the number of respondents). The mean scores for each item ranged from 6.94 to 9.14. It is important to note that the mean scores are relatively high, indicating that all the items were

viewed as quite important by most respondents. All but four items had means that were in the top 30% on the 1–10 importance scale. The high mean scores reflect well on the efforts made to ground item development in the lived experience of consumer/survivors.

A list of the item means in descending order is provided in Appendix E. Not surprisingly, the standard deviations tend to be larger for the items with the lowest means, indicating a wider range in the rating values. The five highest rated items were #40, “The doctor worked with me to get me on medications that were most helpful for me”; #52, “Staff respect me as a whole person”; #25, “Staff listen carefully to what I say”; #56, “There is at least one person who believes in me”; and #51, “I have a place to live that feels like a comfortable home to me.” The five lowest rated items were #2, “Mental health services helped me get or keep employment”; #1, “I have paid work opportunities that are meaningful to me”; #4, “Mental health services helped me in advancing my education if I wanted to”; #16, “There are consumers working as paid employees in the agency where I receive services”; and #8, “Mental health services helped me get reliable transportation.”

It is interesting to note that items regarding employment were rated as less important, although employment was identified as being of high importance in the Phase I member check. The extent to which an inability to work at regular employment, the fear of losing benefits, and low expectations (which were subthemes from Phase I findings) explain the low importance ratings of employment-related items cannot be determined from the Phase II findings. Education items such as #3, “I have a chance to advance my education if I want,” were also rated rather low. The relatively small sample size and the relatively high educational attainment of respondents may have influenced the importance rating of this item.

The small sample size limited the Team’s ability to analyze how particular characteristics of respondents may have influenced importance ratings. The Research Team did look at whether the subgroup of respondents with children and the subgroup who were homeless rated some of the items as relatively more important than did other respondents. To answer this question, the Research Team ran a two sample t-test with unequal variance to determine whether there was a statistically significant difference between parents and nonparents in their mean response on importance to item #55, “I receive support to parent my children.” Of the 114 parents, 94 rated the item’s importance, while 67 of the 101 nonparents rated the item’s importance. The Team used 66 degrees of freedom and found that the observed t-value (0.545) is less than the critical t-value (2.000) at the 95% confidence level and less than the critical t-value (1.671) at the 90% confidence level. Thus, the Team did not find a statistically significant difference in mean importance rating on item #55 between parents and nonparents.

The Team also ran a two sample t-test with unequal variance to determine whether there was a statistically significant difference between respondents who described themselves as homeless and other respondents in their mean response on importance concerning several items that might be affected by the experience of homelessness. Only one item—#47, “I have access to other consumers who act as role models”—showed a statistically significant difference between the means for homeless respondents and those for other respondents. Of the 33 homeless participants, 32 rated this item’s importance, while 175 of the 186 nonhomeless participants rated the item’s importance. The Research Team used 31 degrees of freedom and found that the absolute value of

the observed t-value (-2.0613) was greater than the critical t-value (2.042) at the 95% confidence level. These 32 homeless respondents rated this item as relatively less important than other respondents did. In the final analysis, the item was dropped.

Assessing the Reliability of the Self-Report Prototype Survey

The Research Team assessed the reliability of the survey. There are several different ways to measure reliability. Chronbach's Alpha is one of the most commonly used reliability coefficients. The Alpha is based on the internal consistency of a measure or scale, or how well the items hold together mathematically. It is based on the average correlation of all the items in a scale. Chronbach's Alpha is a coefficient value that can range from 0 to 1.0. Ratings closer to 1.0 indicate higher reliability or internal consistency among the survey items. A Chronbach's Alpha above .70 is considered sufficient to establish adequate reliability.

The Team computed Chronbach's Alpha at several stages. First, the Team computed it on the data gathered on the entire 73 items on the prototype test. Chronbach's Alpha depends on both the length of the test and the correlation of the items on the test. It is possible to have high reliability coefficients even when the average inter-item correlation is small, if the number of items on the scale is large. The example provided by the SPSS statistical package is that, if the average correlation between items is .02 on a 10-item scale, the Alpha is .71. If the number of items increases to 25, the Alpha jumps to .86. Therefore, even with small correlations among the 73 items, there is a chance of having a high reliability coefficient because of the large number of items on the survey.

The Chronbach's Alpha for the data on the 73-item survey was .96, which is considered very high. Besides the large number of items contributing to this estimate, the data are based on only a very small proportion of the potential 219 cases involved in the study. This problem occurred because all of a person's responses were omitted from the analysis if data were missing for even one item on the survey. Overall, there was a small or acceptable amount of truly missing data. However, respondents were given the option of choosing "does not apply to me" for any of the 73 items, and the statistical program counted this response as missing data. There were only 9 cases out of 219 in which the respondent had not selected "does not apply to me" on at least one item. Thus, the Alpha was biased because it was based on a very small proportion of the respondents' answers.

One of the goals in testing the prototype survey was to reduce the number of items, so the Team assessed whether the deletion of a given item would improve the Alpha (items with low correlations with other items generally pull down the Alpha). After a cursory examination of whether Alpha estimates were appreciably higher when an item was deleted, the Team did not pursue this strategy.

The Team also computed Chronbach's Alpha for the reduced set of 42 items. The Alpha remained very high (.95), even with a much larger number of cases in the analysis (N=48). This means there were fewer "does not apply to me" responses on the 42-item survey than on the 73-item survey. The Research Team is confident that the reliability of the 42-item survey is high; however, in Phase III, it will assess the extent to which missing data might be a proxy for variability and the

possibility that the Alpha is high because of a systematic bias (e.g., respondents with certain background characteristics are excluded in the analysis).

Finally, the Team computed an Alpha for the preliminary subset of 10 items advanced to the MHSIP work group for possible inclusion in the quality report. The .82 standardized item Alpha is well within an acceptable range but is lower than that obtained for the 42 items and the 73 items. This analysis was based on an even larger number of cases: 143 respondents did not use “does not apply to me” on any of the 10 items.

The Team will further examine the internal consistency of the ROSI consumer self-report survey during Phase III.

Reducing the Number of Items on the Consumer Self-Report Survey

One of the main goals of Consumer Self-Report Survey prototype test was to use the data to reduce the number of performance indicators or items on the survey. The Research Team reduced the number of items by using a broad array of criteria that included, but was not limited to, statistical analyses of the factor structure, the mean importance ratings of the items, and the reliability analysis. The Team used several criteria in a balanced approach.

Statistical analyses such as factor analysis involve both science and art. Kim and Mueller (1978a & 1978b) suggested that analysts consider “reasonableness,” based on current standards of scholarship in the field, to resolve the number of factors in factor analysis. The Team used objective criteria when possible; but scholarship and research involve subjectivity as well as objectivity. Subjectivity is involved in deciding which criteria to consider and in weighing the criteria in relation to each other to make a decision about whether to delete or retain a given item.

Criteria Used to Evaluate the Consumer Self-Report Survey Items

The criteria considered in evaluating each item are listed below, along with brief descriptions and the general principle(s) that were applied in their use.

Importance rating. The mean importance rating for the 219 respondents in the prototype test. General principle: The higher the mean rating, the more likely the item would be retained.

Factor loading value. The coefficient value in the Varimax rotated factor pattern. General principle: The higher the factor loading value, the more likely the item would be retained.

Response scale distribution and direction. The spread of responses and whether the direction of responses indicates support of recovery. General principle: The item was more likely to be retained if it showed a bi-modal or split spread of responses or if the responses skewed in the direction of indicating a lack of support for recovery.

Phase I theme. Reference to the themes from which an item was generated, based on the Phase I study findings. General principle: Maintain adequate coverage of each important theme.

Items assessing similar content. Identification of items that were very similar in content, meaning, or interpretation. General principle: Reduce redundancy by retaining only one item for a particular content area.

Clarity of wording. Reference to prototype survey results in which respondents were asked to circle words or phrases that were not clear or that they did not understand. General principle: Items containing circled words or phrases were more likely to be considered for deletion.

Phase I member check priorities. Reference to member check findings from the Phase I research, in which participants were contacted after the focus group and asked to give their top three priority items across the topics. General principle: Items representing topics/themes of highest priority were more likely to be retained.

Selected demographic variables (e.g., housing status or parent status) when cross-tabbed with selected mean ratings. General principle: If findings indicated a significant group difference, an item was more likely to be retained to address the needs of a particular subpopulation.

Process Used in Self-Report Survey Item Reduction

A three-member subgroup of the Research Team spent four days in Albany, analyzing the prototype data results to further refine the items and reduce their number. The group received technical support from the staff of the New York SMHA. To facilitate the decision-making process about which items to retain and which to delete, the group divided the range of mean scores of importance into quintiles. This is similar to the approach used in concept mapping (see Trochim, 1989). Thus, the mean scores, which ranged from 6.94 to 9.14, were divided into fifths, resulting in the following tiers:

Tier 1: Mean score of 6.94–7.38 (lowest quintile, 10 items)

Tier 2: Mean score of 7.38–7.82 (13 items)

Tier 3: Mean score of 7.82–8.26 (middle quintile, 21 items)

Tier 4: Mean score of 8.26–8.70 (24 items)

Tier 5: Mean score of 8.70–9.14 (highest quintile, 5 items)

Each item was evaluated according to the criteria listed above. The subgroup of the Research Team began with the 10 items in Tier 1 (the items rated as less important). They reviewed each item, applied all the criteria, discussed the implications, and then documented their rationale for keeping or dropping the item. For example, both items related to employment were in Tier 1. The subgroup elected to keep one of the items, because the respondents in the Phase I member check considered employment very important. In choosing between the two items, the subgroup elected to keep the item that had clearer wording and to which respondents had replied with more negative

experiences. The subgroup believed that this item would be more useful to a service system attempting to identify areas to target for improvement.

After the subgroup reviewed and applied the criteria to all the items in Tier 1, they moved on to Tier 2. In another example, the item regarding consumer peer advocates and the item regarding consumer role models were both in Tier 2. The subgroup decided that these two items were similar, as a peer advocate would often function as a role model as well. They elected to keep the item on consumer peer advocates, as it had a higher importance mean and individual responses were more evenly distributed across the response scale (thus, it discriminated better among the respondents). Once the subgroup completed work on a given tier, they moved on to the next, ending with Tier 5.

It might be expected that the number of deletions would decrease as the subgroup progressed from Tier 1 (lowest quintile) to Tier 5 (highest quintile), and this was roughly the case. Sixty percent of the indicators were deleted from Tier 1; 54% from Tier 2; 57% from Tier 3; 29% from Tier 4; and none from Tier 5.

At the conclusion of the Albany session, the Research Team subgroup had selected 41 items to retain in the consumer self-report survey. The full Research Team reviewed this work in a teleconference, paying particular attention to the items that had been dropped. The Team revisited the documented rationale for either keeping or dropping an item and reexamined the item in light of the criteria. One dropped item was returned to the self-report survey item set, bringing the total to 42 items. Appendix F shows the original 73 self-report items organized under the themes and subthemes identified in Phase I. The items marked with an asterisk (*) were retained in the 42-item survey.

The methods the Research Team used to reduce the number of survey items had strengths and limitations. By using multiple criteria, the Team was able to take into consideration various factors in making the decision to delete or retain an item. By using multiple evaluators, the Team reduced the risk of personal bias influencing decisions. The inclusion of such criteria as importance ratings and member check priorities emphasized the project's commitment to build from the ground up and to maximize consumer voice.

While the strengths of using multiple criteria probably outweigh the limitations of doing so, it should be noted that inconsistencies are inherent in this approach. Other items might be selected for retention if the selection process were replicated, even if the same criteria were used. In addition, the process of weighing the criteria in relation to one another was difficult and time intensive. Fortunately, the group was able to meet over the course of several days.

Factors/Components of the 42-Item Survey

The factor analysis of the 42-item self-report survey was rerun using the prototype data set. This resulted in the identification of eight factors or components: person-centered decision making and choice; invalidated personhood; self-care and wellness; basic life resources; meaningful activities and roles; peer advocacy; staff treatment knowledge; and access. The fact that items stated as hindrances to recovery largely grouped together is seen at this point in time as a potential construct

or subscale. Whether this is the case or an artifact of the method will be further explored during larger scale pilot testing. The items on the final survey break out into these factors as follows:

Person-Centered Decision Making and Choice

Staff treat me with respect regarding my cultural background (think of race, ethnicity, religion, language, age, sexual orientation, etc.).

Staff believe that I can grow, change, and recover.

Staff give me complete information in words I understand before I consent to treatment or medication.

Staff listen carefully to what I say.

Staff stood up for me to get the services and resources I needed.

Staff encourage me to do things that are meaningful to me.

Staff see me as an equal partner in my treatment program.

I have a say in what happens to me when I am in crisis.

The doctor worked with me to get on medications that were most helpful for me.

I have information and/or guidance to get the services and supports I need, both inside and outside my mental health agency.

Staff use pressure, threats or force in my treatment.

I lack the information I need to uphold my client and basic human rights.

Mental health services helped me get medical benefits that meet my needs.

There is at least one person who believes in me.

There are consumers working as paid employees in the mental health agency where I receive services.

My treatment plan goals are stated in my own words.

Invalidated Personhood

I am treated as a psychiatric label rather than as a person.

I do not have the support I need to function in the roles I want in my community.

Mental health staff interfere with my personal relationships.

Staff do not understand my experience as a person with mental health problems.

Mental health services have caused me emotional or physical harm.

The mental health staff ignore my physical health.

I do not have enough good service options to choose from.

Staff respect me as a whole person.

Mental health services led me to be more dependent, not independent.

Self-Care and Wellness

My family gets the education or supports they need to be helpful to me.

Mental health staff support my self-care or wellness.

Mental health staff help me build on my strengths.

My right to refuse treatment is respected.

I can see a therapist when I need to.

Basic Life Resources

I have reliable transportation to get to where I need to go.

I have housing that I can afford.
I have enough income to live on.
I have a place to live that feels like a comfortable home to me.
Mental health services helped me get housing in a place I feel safe.

Meaningful Activities and Roles

Mental health services helped me get or keep employment.
I have a chance to advance my education if I want to.
I am encouraged to use consumer-run programs (for example, support groups, drop-in centers, etc.).
Services help me develop the skills I need.

Peer Advocacy

There was a consumer peer advocate to turn to when I needed one.

Staff Treatment Knowledge

Staff lack up-to-date knowledge on the most effective treatments.

Access

I cannot get the services I need when I need them.

Creating a Final Draft of the ROSI Self-Report Survey

The final 42 items were crafted into a refined adult Consumer Self-Report Survey as one of the ROSI measures. This survey, with revised four-point response scales and accompanying demographic data section, can be found in draft form in Appendix G. The 42 self-report items have a Flesch-Kincaid Grade Level test mean reading score of 5.7 (1.0 minimum and 12.0 maximum).

Subset of ROSI Self-Report Items to Add to the MHSIP Quality Report Version 2.0

As discussed earlier, the MHSIP community has been in the process of developing a second generation report card or quality report that includes recovery indicators. Members of the Research Team have worked closely with MHSIP in this process. While MHSIP supported the development of the ROSI 42-item self-report survey, the group also requested that the Research Team select a subset of several items from that survey to be incorporated in the MHSIP Quality Report Version 2.0.

Toward that end, the Research Team first selected 18 items based on the factor analysis of the 42-item set. The Team then applied a Q-sort (queue sort) process to the items. Each Team member rated each of the items using a three-point importance scale. Six items were to be rated “3” (highest importance); six items were to be rated “2” (medium importance); and six items were to be rated “1” (lowest importance). An average rating was then computed from the five scores for each item. The scores for each of the 18 items ranged from 1.2 to 2.8. Nine items had an average score of 2 or above and were retained. A tenth item was included after discussion. The 10-item question set was analyzed and was found to have a Flesch-Kincaid Grade Level reading score of 4.4, with a 2.3 minimum and 10.9 maximum reading level for individual items.

The 10-item subset was submitted to MHSIP for inclusion in the Quality Report Version 2.0. Appendix H contains this subset. Certain caveats should be noted. This subset is not a stand alone measure, nor is it a psychometrically based short version of the ROSI Self-Report Survey. The 10-item subset is being advanced in conjunction with the full 42-item ROSI self-report measure. Further work will be needed in Phase III to create a psychometrically sound short form of the ROSI.

Further Refinement of the Administrative-Based Indicator Set

Administrative-based performance indicator measures are common in the mental health field. In 2001, Substance Abuse and Mental Health Services Administration (SAMHSA) published an announcement in the *Federal Register* of its Block Grant Performance Measures for states, the Uniform Reporting System (URS). The URS contains both “basic” and “developmental” performance indicator tables. Reporting of the URS basic tables began in 2002, with full reporting by all states expected within a few years. As a part of this effort, the 16-State Study on Mental Health Performance Measures was a landmark joint State-Federal initiative to apply standardized definitions and obtain comparable performance and outcome indicators on public mental health systems across the states. The study focused on 32 mental health performance indicators, and several indicators were based on administrative data. Some examples of the data that are collected are inpatient readmission rates within 30 days and 180 days; the use of new atypical antipsychotic medications in state psychiatric hospitals; seclusion and restraint rates in psychiatric hospitals; and contact with the community mental health program within seven days of hospital discharge. Administrative-based data also provide outcome measures, such as the percentage of homeless people and mortality rates. More information on the URS indicators is available from the Center for Mental Health Services.

The Research Team identified several indicators that lend themselves to administrative-based data inquiries. These items do not lend themselves to consumer/survivor self-report, because service recipients would likely not have the knowledge or access to the data needed to answer the questions. Instead, the administrative items could best be answered through data provided directly by program or administrative staff, and could be collected or analyzed best at the agency or authority level (i.e., behavioral health care organizations, regional mental health authorities, and state mental health authorities). For example, a typical consumer/survivor probably would not know about the composition of the provider’s governing board, how many board members are primary consumers/survivors, or the proportion of funding provided to peer support and consumer-operated services. Staff members in a provider organization could answer such questions.

As noted earlier, a January 2003 Research Team meeting involved rethinking, refining, and editing the recovery performance indicators. The meeting resulted in the development of 27 proposed performance indicators based on administrative data. The 27 items were distributed across the Phase I study domains as follows: Basic Material Resources (0); Self/Whole Person (0); Hope/Sense of Meaning and Purpose (0); Social Relationships (0); Choice and Independence including coercion elements (6); Meaningful Activities (0); Peer Support (3); Formal Services

(17); and Formal Service Staff (1). The administrative data item set underwent extensive refinement along a separate but parallel track from the self-report item set.

The first step in the process of refining the administrative performance indicator set took place in January 2003. This step entailed the preparation of a crosswalk between the 27 administrative data items and the three sets of administrative performance indicators being considered for the MHSIP Quality Report Version 2.0. The MHSIP work consisted of a specific performance indicator, such as “seclusion,” with one or more operational definitions to measure that indicator. For example, one operational definition for seclusion was “hours of seclusion as a percentage of client hours.” This administrative indicator was further defined as the total number of hours that all clients spent in seclusion divided by the sum of the daily census (excluding clients on leave status) for each day (client days) multiplied by 24 hours. There were three sets of MHSIP indicators: (1) a set of indicators that already had standardized definitions (such as the seclusion example); (2) a set for which multiple definitions were in use; and (3) a set that required the development of definitions.

Some of the administrative data items developed in the National Research Project fit into seven of the proposed indicators for the MHSIP Quality Report Version 2.0. These items seem to fall into MHSIP’s proposed administrative indicators on seclusion and restraints, medication errors, cultural competence, involvement in the criminal justice/juvenile justice system, percentage of persons receiving services in the least restrictive service setting, and reduced substance abuse impairment.

Twenty of the administrative data items developed by the Team did not seem to fit into the existing MHSIP taxonomy of administrative indicators. The Research Team condensed these 20 items into 12 performance indicators that included advance directives, involuntary inpatient commitments, involuntary outpatient commitments, recovery mission statement, consumer selected outcomes, office of consumer affairs, consumer involvement in governance and policy, consumer employment in mental health systems, ratio of direct care staff to clients, peer/consumer-operated services funding, trauma services, and public awareness.

Except for seclusion and restraints, the operational definitions of the remaining five applicable MHSIP indicators did not address the specific concerns identified by the Research Team. The 12 new performance indicators did not have operational definitions. Through a series of teleconferences and the incorporation of feedback from participating SMHAs and the MHSIP Workgroup, the Research Team generated specific operational definitions (i.e., numerators and denominators) for each of the remaining 17 administrative indicators.

For example, one item was stated as “the percentage of clients under involuntary outpatient commitment.” The Research Team defined the numerator as the number of clients who received involuntary outpatient commitments during the reporting period and the denominator as the total number of clients who received outpatient services during the reporting period. The end result of this effort was the development of 30 operational definitions that corresponded to a final group of 19 administrative recovery performance indicators.

The Research Team then designed a survey to elicit feedback on the 19 indicators and 30 corresponding operational definitions. The survey followed the design of a performance measures survey that had been developed by the Outcomes Roundtable for Children and Families. The survey solicited feedback as to (1) the feasibility of implementing each of the operationalized measures (i.e., rating each as very feasible, fairly feasible, limited feasibility, not at all feasible); (2) the importance of each measure for improving the system's recovery orientation (very important, fairly important, limited importance, not at all important); (3) whether the data articulated in the measure were currently being collected (yes or no); and (4) comments. The Research Team surveyed the 10 participating SMHAs. The Team requested that each SMHA complete only one survey, involving key staff as needed.

The Research Team also surveyed the nine members of the MHSIP Consumer Expert Panel and the members of the National Association of Consumer/Survivor Mental Health Administrators (NAC/SMHA) to continue the process of grounding the work in the lived experience of consumer/survivors. The Team selected these two consumer/survivor groups because they have working knowledge of performance indicators and outcome measurement.

The initial request to participate was through a teleconference conducted with each of the targeted participant groups, followed up with a cover letter, instructions, and the survey. Participants were encouraged to use the comment section to revise or suggest alternatives for the operational definitions and to identify issues, concerns, and response burden demands associated with any of the proposed indicators. The Research Team made one follow-up request to members of these groups.

Nine of the 10 SMHAs and three NAC/SMHA members responded to the survey. The Research Team compiled the results; a complete report is contained in Appendix I. The Research Team members evaluated each administrative item in terms of importance rating, feasibility rating, and respondent comments. The items that the majority of the respondents considered feasible, important, and clear were given more weight. The Research Team considered the relationship of each administrative indicator to the self-report indicator set, to guard against the loss of critical content by virtue of the topic being eliminated from both indicator sets. For example, the prototype self-report results indicated that a self-report item on advance directives, regardless of how it was worded, was confusing to many respondents. They had no exposure to advance directives and couldn't answer such a question. Therefore, advance directives had to be addressed through administrative data collection. The Research Team also weighed whether states already collected the information. For each administrative indicator, the Research Team wanted to identify at least one SMHA that already successfully collected that data, to ensure that data collection was feasible.

The Research Team used this review process to refine the ROSI Administrative Data Profile as the second part of the ROSI measure. The final version consists of 16 indicators and 23 items. All performance indicators are operationally defined at the mental health authority level; most items also have a provider level equivalent, which can be modified for provider level application. Appendix J contains the ROSI Administrative Data Profile, with the accompanying Authority Characteristics and Provider Characteristics forms, and the Profile is available for pilot testing. The following list organizes the Administrative Data Profile under the Phase I themes.

The ROSI Administrative-Indicators Cross Walk to Phase I Study Themes

Recovery Theme: Peer Support

Performance Indicator: Independent Peer/Consumer Operated Programs

Performance Indicators (2): Peer/Consumer Delivered Services Funding

Performance Indicator: Consumer Employment within Mental Health Systems

Performance Indicator: Affirmative Action Hiring Policy

Recovery Theme: Choice

Performance Indicator: Advance Directives

Recovery Theme: Formal Service Staff

Performance Indicator: Direct Care Staff to Client Ratio

Recovery Theme: Formal Services

Sub-Theme: Helpful System Culture and Orientation

Performance Indicators (2): Recovery Oriented Mission Statement

Performance Indicator: Consumer Involvement in Provider Contract Development

Performance Indicators (2): Office of Consumer Affairs

Performance Indicators (2): Consumer Inclusion in Governance and Policy

Sub-Theme: Coercion

Performance Indicator: Involuntary Inpatient Commitments

Performance Indicator: Involuntary Outpatient Commitments

Performance Indicators (2): Seclusion (MHSIP's Proposed Indicator)

Performance Indicators (2): Restraint (MHSIP's Proposed Indicator)

Sub-Theme: Access to Services

Performance Indicator: Jail Diversion Service Provision (related to MHSIP's proposed indicator on involvement in the criminal/juvenile justice system)

Performance Indicator: Integrated Substance Abuse and Mental Health Service Provision (related to MHSIP's proposed indicator on reduced substance abuse impairment).

Performance Indicator: Trauma Service Provision

Limitations

This subsection discusses general limitations in the National Project's work. In a complex project conducted in several phases such as this one, the limitations of a previous phase may have an impact on subsequent work. The Research Team identified several limitations in Phase I efforts. These included the fact that the study participants were not fully representative of the population of public mental health service recipients or of the general population of people with psychiatric disorders and disabilities. Also, determining the relative importance of the many ideas generated during the focus groups in Phase I was beyond the scope of the research method used. (A full description of the limitations of the Phase I work is available in the Phase I research report, pp. 77–78).

The Research Team attempted to overcome some of the Phase I limitations in Phase II research. In Phase II, there was a greater range of diversity in respondent demographics. For example, in Phase

I, only 1 of 115 focus group participants was homeless; of the prototype testing respondents, 33 (15%) were homeless.

The Research Team used a process of priority setting in the member check follow-up in Phase I to gain an idea of which themes were most important in evaluating mental health services. Once the ideas from the Phase I study were converted into performance indicators in Phase II, the relative importance of each indicator was determined during the prototype testing. Thus, while the Research Team could not fully determine in Phase I which ideas or domains were most or least important, owing to the qualitative methodology, the Team ultimately did determine the average importance rating for each performance indicator on the basis of ratings provided by Phase II participants. The average importance ratings were a primary input into the process of reducing the total number of performance indicators.

Many “natural” and “man-made” problems can limit the full potential of efforts to measure performance, although the chance of successfully measuring performance can be improved (Eddy, 1998). One of the “natural” problems involves the extent to which agencies that deliver care can truly influence or control a given recovery outcome versus the extent to which an outcome is determined by factors that are beyond the agency’s ability to control. The Phase I work and the research of others demonstrate that many factors influence the process and outcome of recovery. While care was taken in Phase II to develop performance indicators in areas that mental health systems do (or may potentially) influence, the impact of formal services and supports is usually not the only factor affecting recovery. For example, while performance indicators having to do with basic resources such as income and housing can be influenced by the delivery of mental health services, they may also be influenced by the local unemployment rate, cost of living, and housing market.

Part IV. Initial Thinking Regarding Phase III of the National Project

In Phase III of the National Project, the Research Team proposes to pilot test the set of Recovery Oriented System Indicators (ROSI) measures that include the consumer self-report survey and the administrative data profile. Pilot tests of the ROSI measures will serve several functions, chief among them, further psychometric testing of the measures. Implementation of the administrative data profile will be assessed. The costs associated with administering and analyzing the ROSI will be estimated, and the potential for benchmarking program performance will be explored.

Ideally, a rigorous pilot test of the ROSI would take place in a fairly tightly controlled fashion. For example, selected sites would be carefully chosen, and the self-report measure would be administered to a large random sample of those receiving services. A well-designed and controlled pilot test has certain advantages, including the fact that it supports the internal validity of the measure. When sufficient resources are lacking to mount a carefully controlled formal pilot study (as is true in the current climate), a pilot can be done by accumulating a large amount of data on the instrument being tested, using multiple samples gathered from diverse sites. This more pragmatic alternative to formal pilot testing nevertheless allows rigor in the analysis of the data and can be structured to answer crucial questions about the design, reliability, validity, and utility of the ROSI measures. The potential for mounting a pilot at multiple sites seems good; several systems (local as well as regional) have expressed an interest in using the ROSI measures. Indeed, one participating state research partner has already pilot tested the ROSI Consumer Self-Report Survey.

The New York Pilot

New York, one of the participating states in the National Research Project for the Development of Recovery Facilitating System Performance Indicators, has conducted a preliminary pilot of the ROSI Consumer Self-Report Survey. During the summer and fall of 2004, the New York State Office of Mental Health (NYSOMH) partnered with peer-run agencies and peer advocacy programs to conduct a consumer assessment-of-care project in the adult outpatient service system. The overall goal of the New York project was to develop a basis for quality improvement in the full spectrum of community-operated public mental health service programs serving adults across the state.

The study assessed the validity, reliability, and comparability of four consumer assessment-of-care survey instruments, using an approach in which peers (consumers) were involved in the administration of the surveys. The four instruments were the 42-item draft ROSI Consumer Self-Report Survey; New York State's existing Mental Health Services Survey (MHSS); New York's Quality of Life Assessment; and the federal Mental Health Statistics Improvement Program (MHSIP) Consumer Survey Version 1.0. The ROSI Administrative Data Profile was not included in this study, as it is not a consumer survey.

To maximize the diversity of the sample population, New York was divided into four regions: two upstate urban and rural regions and two downstate urban and suburban regions. Only counties with a peer-run organization were considered (43 of 62 counties have peer-run or peer-advocacy organizations). Two counties were randomly selected from each of the four regions, for a total of eight participating counties. A peer program in each participating county was identified to help coordinate the survey administration. Two consumers were nominated by each program to serve as peer administrators for the survey. They received a one-day training to support their role in the project, publicized the surveys, preregistered up to a maximum of 50 participants per site, organized refreshments on site, and helped NYSOMH staff administer the surveys.

NYSOMH staff and peer program partners enlisted consumers to participate in the study from a mix of nonresidential community programs, including case management, outpatient clinics, drop-in centers, MICA (Mental Illness Chemical Abuse) programs, clubhouses, psychosocial rehabilitation, medication management programs, and others. A stipend was provided to participants to acknowledge the value of their time and to defray travel and child care expenses. Surveys were administered at the peer program and were available in English and Spanish. Consumers who volunteered to participate in the survey but were unable to attend on the day of survey administration were offered the option of mailing in the survey. Overall, 415 consumers volunteered to participate in the survey. Of those, 388 (93%) completed the survey—378 (97%) in person and 10 (3%) by mail.

The total time for participants to complete the four surveys in the group setting ranged from 25 minutes to 1.5 hours. Some consumers required assistance in English or Spanish because of literacy challenges (the surveys were at the sixth grade reading level). Data quality was good, with 316 of 388 participants (81.4%) answering all questions on all four surveys.

Data analysis is currently under way. Preliminary findings suggest that the ROSI may be more sensitive than the MHSIP or MHSS in identifying dissatisfaction with mental health services. Previous studies comparing the MHSS and the MHSIP have found that the instruments perform similarly, with the majority of consumers rating services positively (Dornan & Kirk, 2003). Context of survey administration does have an impact, and using a peer-to-peer method increases the variability in the responses (Uttaro, Leahy, Gonzalez, & Henri, 2004). The data will be used to examine the psychometric properties of the ROSI and to identify any items that may need to be refined as part of Phase III of the national project.

Developing a Process for Scoring the ROSI Measures

The proposed Phase III will help the Research Team devise the means to appropriately analyze and report the findings of the ROSI measures. For example, to ease arriving at a total item score, the Research Team revised the frequency response scale to four points. The prototype version of the ROSI Consumer Self-Report Survey was composed of two response scales that differed in the number of response options. If scored without conversion to a common metric, the items that use the six-point frequency response contribute more heavily to the mean score than the items that use the four-point agreement scale; this was not the intent. Converting the six-point frequency scale to four-points was done by combining "never" with "rarely" and by combining "almost always" with

"always." While our prototype findings suggest this may result in a loss of specificity, it simplifies arriving at a combined total score across all items.

The preliminary factor analysis suggests that recovery orientation is a multidimensional construct. The question of whether the self-report survey includes subscales that should be scored separately requires further investigation.

Psychometric Testing of the Measure Using Data from Pilot Testing

The psychometric properties of a research instrument largely concern the reliability and validity of the instrument, which are assessed through a variety of statistical analyses. Psychometric testing is undertaken to describe an instrument's reliability (how stable or consistent a measure the instrument is) and validity (how well it measures what it seeks or claims to measure). Psychometric testing examines the set of questions the subjects complete (known as test items) and how these items are answered by large groups of people. A scale or test is generally considered valid if it successfully measures what it is supposed to measure. An unreliable measure always lacks validity, but a reliable measure is not necessarily valid. The Research Team proposes to test the ROSI's convergence with other recovery measures and identify discriminating qualities that distinguish it from other instruments. Such analyses will move the National Research Project toward establishing the construct validity of the ROSI measures.

The Team proposes to use several statistical procedures to establish the psychometric properties of the ROSI survey, including the following:

- ◆ Computing descriptive statistics—means, standard deviations, and item total correlations. Item means and standard deviations obtained from the prototype test of the ROSI Consumer Self-Report Survey suggest that the means are reasonable representations of the data and show sufficient variation among the items. Descriptive statistics have not been computed on the ROSI Administrative Data Profile.
- ◆ Conducting factor analysis to assess the factorial structure of the theoretical construct. Factor analyses of the prototype test data suggest a multifactorial structure for the ROSI Consumer Self-Report Survey, which will be examined further with a larger pool of pilot test data.
- ◆ Computing Chronbach's Alpha coefficient for the ROSI Consumer Self-Report Survey as a whole, and for each of its potential subscales, to establish the scale's internal consistency (how well the survey items hang together). The Alphas obtained from the prototype testing suggest that the consumer self-report measure has good internal consistency. Pilot testing will allow the Research Team to examine potential biases that were introduced by using a relatively small, nonrandom sample of cases for the early analyses.
- ◆ Exploring potential ways to establish structural and factorial relationships between the ROSI Self-Report Survey and the ROSI Administrative Data Profile.

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- ◆ Computing intra-class correlation coefficients to move toward establishing both measures' test-retest reliability, or the extent to which repeated measurements made under constant conditions provide the same result. This analysis will require administering the measures at two points relatively close in time. An attempt to account for intervening variables that occur between the first and second times will likely require the collection and analysis of additional data, such as event data, psychiatric/service system data, and other life and organizational event data.

The Research Team has developed a demographic section for the ROSI Consumer Self-Report Survey, a short Authority Characteristics Form and a short Provider Characteristics Form that accompanies the ROSI Administrative Data Profile to capture variables that may be associated with the ROSI measures in important ways. Chi-square statistics and analysis of variance (ANOVA) will be used to examine differences in the demographic characteristics of respondents (Self-Report Survey) and organizations (Administrative Data Profile). In addition, the Research Team has developed a ROSI Pilot Information, Guidelines and Process Form that provides guidelines for administering these measures and captures important measure administration information necessary for exploring bench marking. This latter form can be found in Appendix K.

The Research Team will also consider using Item Response Theory (IRT) in the testing of the ROSI Self-Report Survey where, for example, test properties are “sample free,” compared with Classical Test Theory, where test properties are “sample dependent.” Other benefits may make IRT worthwhile.

The ROSI Administrative Data Profile can be pilot tested along with, or separately from, the ROSI Self-Report Survey. Because the ROSI Administrative Data Profile set overlaps with the MHSIP quality report indicators, we hope participating State Mental Health Authorities (SMHAs) will test the ROSI Administrative Data Profile in conjunction with other quality report performance indicators.

Benchmarking Performance

A growing number of states say they have a goal of promoting recovery through the provision of public mental health services. Many more intend to move in the direction of recovery in the near future. The proposed Phase III may help the field develop normative recovery performance standards over time. Benchmarking involves having a set standard against which to judge performance. The Task Force on the Design of Performance Indicators Derived from the MHSIP Content (1996) advises, “Carefully crafted decision rules should be developed in advance and applied uniformly in the application and utilization of performance indicator findings” (p. 42). That task force states that high performance and low performance on any given indicator can be defined as two standard deviations above and below the statistical mean or average performance ratings. In that group's terms, a designation of overall high or low performance must be based on multiple performance indicators, never on a single indicator.

In an approach proposed by the developers of the Experience of Care and Health Outcomes (ECHO) survey, the standard for high performance is set at *the most desirable outcome* (Cubanski,

Shaul, Eisen, Cleary, & Tesoro, 2002). In one proposed scheme, core values for computing rates accentuate the most desirable outcomes with a value of “1” and give a “0” for all other response options (e.g., on a four-point frequency scale, only the response “always” to “get urgent treatment as soon as needed” is scored affirmatively, or with a “1”). There is an exception to this rule: In the overall rating of counseling and treatment, response choices of 9 or 10 on a scale from 0–worst to 10–best are both scored “1.” While means and standard deviations could still be used, such a weighted scoring scheme raises the bar for what constitutes acceptable performance.

In another scenario, any demonstration of significant incremental progress or movement of a performance indicator in the proper direction (e.g., away from hindering recovery and toward facilitating recovery) could serve as a management tool for setting targets for change and measuring improvements in performance as a system undertakes the process of transformation.

When the proposed pilot testing of the ROSI measures gets under way, the Research Team will be able to put forth a range of observed means (statistical averages) by possible service configuration or site. Preliminary data from the prototype test suggest that important variations exist by site or by state. For example, for “I have housing that I can afford,” the means ranged from 3.05 to 5.12 across the seven participating states. For the question “There are consumers working as paid employees in the mental health agency where I receive services,” the means ranged from 1.95 to 4.22. For the question “I have a say in what happens to me when I am in crisis,” the means ranged from 2.57 to 5.11. The Research Team will attempt to reduce the inaccuracy of service system comparisons by refining definitions and sampling methods, and considering statistical approaches such as case mix adjustment.

In the proposed Phase III, the Research Team is interested in exploring the development of benchmark performance standards, using mean scores and other scoring schemes. The adoption of such standards and efforts to minimize the process of “gaming” (the distortion of data to appear in a more favorable light) (Kimmel, 1983) should improve the process of performance measurement. Certain conditions—such as setting realistic expectations, participatory development of performance indicators and benchmarks, and using performance indicators for comparisons only with comparable programs or consumer profiles—could help ensure the integrity of the process (Wholely and Hatry, 1992).

Other Considerations in Recovery Performance Measurement

The process of performance measurement has costs; Eddy (1988) advocates identifying these costs. Whether, or when, to assess the costs of administering and analyzing the ROSI will be considered as part of the proposed piloting.

In the proposed Phase III, the Research Team will create a psychometrically sound ROSI-SF (Short Form) Consumer Self-Report Survey and further streamline the ROSI Administrative Data Profile. The Research Team will also consider examining the relationship between level of personal recovery and the extent to which recovery orientation has been promoted or hindered by the system. This will entail adding a means to measure individual recovery to accompany the

ROSI pilot in some sites. To conduct these analyses, the Research Team will be augmented by consultants with additional statistical expertise.

Creating a ROSI Users Manual

All measures should have a manual that instructs users on how to administer the instrument(s) in a standardized manner; provides users with technical information and specifications on the tools; and recommends processes for data collection, scoring, analysis, and interpretation. The development of a ROSI users' manual will be a major contribution of the proposed Phase III.

Linking with Decision Support 2000+

As this report goes to press, the Research Team has been informed that the ROSI measures will become incorporated into the mental health data standards and technology platform of Decision Support 2000+ (DS2000+). The DS2000+ Initiative has developed standards for collecting and reporting population, enrollment, encounter, financial, organizational, and human resource data as well as for system performance and consumer outcomes measurement. It has also developed an online information system (www.ds2kplus.org) that provides tools for a wide range of users to conduct surveys; collect, store, analyze, and benchmark data; and share information across the field. Please monitor the DS2000+ initiative for further developments.

Part V. Summary and Recommendations for Using the ROSI Measures

The National Research Project for the Development of Recovery Facilitating System Performance Indicators has undertaken a series of intensive efforts to learn what promotes recovery and what impedes recovery in the lives of people with serious psychiatric disorders. The rigorous qualitative research carried out in Phase I of the study carefully examined mental health recovery and grounded the findings in the lived experience of mental health consumers. The Phase I research resulted in a comprehensive understanding of important processes, services, and supports that tend to help or hinder the process of personal recovery. Data gathered in Phase I provided the basis for the Phase II development of program and system-level recovery performance indicators.

The National Research Project has had significant mental health consumer/survivor input at every stage, including several consumer researchers on the Research Team, consumers serving as focus group facilitators and participants, consumer involvement in rechecking the initial interpretation of findings, and consumer involvement in a Mental Health Statistics Improvement Program (MHSIP) Web-based process of rating and commenting on proposed indicators. Consumers/survivors were involved in formulating the indicator set and provided feedback on the wording of particular self-report indicators, in determining the relative importance of each indicator, and in field testing a prototype of the ROSI Consumer Self-Report Survey. Data were gathered from service recipients in several states using a draft prototype of the ROSI Consumer Self-Report Survey. Consumer affairs officers were involved in review and feedback for the draft ROSI Administrative Data Profile as well.

Phase II of the project resulted in the development of a set of ROSI assessment tools that includes the following:

1. A 42-item ROSI Consumer Self-Report Survey that examines service recipients' ratings of factors in the local mental health system that facilitate or impede mental health recovery.
2. A 23-item ROSI Administrative Data Profile that gathers crucial information on a variety of indicators of the recovery orientation of a local, regional or state mental health system that can best be assessed, gathered, formulated, and communicated by administrative staff.
3. A 10-item set of ROSI Consumer Self-Report Survey that has been advanced for consideration as part of the revision of the comprehensive MHSIP Quality Report Version 2.0.

Additional tools include a uniform demographic section in the ROSI Consumer Self-Report Survey, an Authority Characteristics Form and Provider Characteristics Form accompanying the ROSI Administrative Data Profile, and a Pilot Information, Guidelines and Process Form to guide and document the process used in pilot testing of the ROSI.

The current national policy environment supports efforts to improve and expand the recovery orientation of mental health programs and systems. The Substance Abuse and Mental Health Services Administration (SAMHSA), which is the federal mental health agency, and other departments in the federal government are increasingly emphasizing the need to transform local mental health systems so that services and supports facilitate resilience and recovery. In the coming months and years, federal resources will be targeted to support system transformation efforts. Programs will be encouraged or required to help people with psychiatric disabilities develop consumer driven individual recovery plans. Statewide recovery plans will be required that demonstrate movement toward fulfilling the goals, needs, and preferences of consumers and ensuring that they have access to the resources they need to achieve a full life in their community.

In such a climate, performance indicators that provide a data-based means to measure the recovery orientations of programs and systems will be crucial management tools. Many administrators, researchers, agencies, and programs are looking for instruments to measure the recovery orientation of their mental health programs and to assess the recovery outcomes that mental health recipients achieve.

Caveats for Using the ROSI Measures

Administrators, agencies, evaluators, and advocates are invited to participate in the development of a multisite pilot of the ROSI measures, as described below. People may be tempted to use the ROSI without waiting for the pilot test, but the Research Team does not recommend this. The psychometric properties have not yet been determined, and the measures may be altered somewhat before they achieve final form. There is no users guide or analysis package to guide the use of the ROSI and the analysis of data.

Using the 42-item ROSI Self-Report Survey without the allied use of the ROSI Administrative Data Profile is *not recommended*. Data generated from the ROSI Consumer Self-Report Survey are incomplete; the ROSI Administrative Data Profile gathers data on important indicators of the recovery orientation of a system that are not covered in the consumer survey.

People who are considering using the ROSI should be aware that the self-report measure is not intended to serve as an outcome measure of personal recovery. The ROSI does not provide information about the relationship among the process of personal recovery, recovery outcomes, and the performance indicators of the agency or system.

Despite these issues, the Research Team is aware that by placing the ROSI in the public domain, it is enabling agencies and evaluators to pick up the self-report tool as it exists and incorporate the measure into their work. Some people may elect to use the self-report measure as a free-standing instrument, without collecting the administrative data set.

While the Research Team retained consumers' phrasing in some items and reduced the average reading level for the 42-item survey, a few items require a high reading level. Some consumers may not have the literacy level needed to read or understand these items. The Research Team strongly recommends that someone (e.g., a volunteer or peer specialist) be available to assist

respondents during administration of the measure. This person can provide reading support and answer questions. It is also helpful to have a written set of definitions on hand that explains and defines which services and which staff the respondent is evaluating, as was done in the Phase II prototype test.

The New York State Office of Mental Health has translated the 42-item ROSI Consumer Self-Report Survey into Spanish. Because of differences in regional Spanish dialects and respondent literacy levels, the Research Team strongly recommends that an interpreter be available to Spanish-speaking respondents during the administration of the survey. The ROSI survey is not available in other languages at this time, but the Research Team is open to working with interested parties in such efforts.

The Research Team makes the following requests of any person or agency that chooses to move forward in using the ROSI measures in the near future:

First, the Research Team would like to be informed of anyone who is using the ROSI measures. Contact the Research Team through either of the principal investigators: Steven Onken <so280@columbia.edu> or Jeanne Dumont <jdumont@lightlink.com>.

Second, the Research Team would like anyone who uses the ROSI measures to use them as currently formatted and not shift the items around, change the wording of any of the items, or shorten the measures by gathering data only on a subset of items.

Third, the Research Team would like anyone using the ROSI Consumer Self-Report Survey and/or the ROSI Administrative Data Profile to maintain their data set and agree to consider sharing their data with the Team when the Phase III pilot test of the ROSI is under way. This request will be subject to approval by the local site's research review, confidentiality, and Institutional Review Board processes. The local site would continue to "own" the data but would share the data set with the Research Team.

Fourth, the Research Team would like anyone using the ROSI to gather a small set of additional data that includes self-report survey respondent demographic variables, agency/system-level descriptors, and methods of data collection. These forms are included in the appendices.

By agreeing to these conditions, those using the ROSI measures will help advance recovery research in several ways. The data gathered will be added to the data from other pilot sites to (1) improve the analysis of the statistical properties of the measures (psychometric testing); (2) improve the field's understanding of how program/site/system-level variables influence findings; (3) build a database on how different subpopulations may differ in their responses to the ROSI; and (4) create a set of national norms that will help in setting benchmarks for improvements in programs and systems.

The larger the database that the Research Team can acquire, the better the chances of conducting a thorough and sound analysis. Creating a central repository for ROSI data from many sites will

advance the field's understanding of recovery and will allow refinements in the ROSI measures over time.

At this time, the research team is working with the DS2000+ initiative as to a limited Phase III effort. No funds are available to support technical assistance to those using the ROSI on their own. But it may be possible to arrange a contract for technical assistance, if the sponsoring agency has the resources.

The ROSI Measures as a Tool for System Transformation

The federal government is committed to identifying and supporting processes of transformation that profoundly change the way mental health programs and systems operate. Many state mental health authorities, county and local planning regions, and mental health provider agencies have already made a firm commitment to embrace, and to operate from, a recovery orientation; some programs and systems have been making efforts in that direction for several years. The need has never been greater for well-grounded evaluation and research tools that can accurately assess a system's recovery orientation, and for a set of uniform recovery performance indicators that can be adopted and used by local, regional, and state mental health authorities.

The ROSI measures should be considered among an emerging set of “tools for transformation” that are available to policymakers, administrators, planners, evaluators, consumers, family organizations, advocates, and others involved in efforts to fundamentally transform state, county, and local mental health systems. The ROSI measures are an important resource for systems as they plan for change, strategically and intensively target their efforts and resources, and seek to understand the impact of their work as they move forward to shift mental health programs and systems to a recovery orientation.

System transformation is a tall order, and system change efforts are often complex and difficult to target, track, and measure. The ROSI, used alone or with other recovery assessment tools, will allow and support systematic analyses and evaluation of change efforts. The ROSI gives programs and systems a means to demonstrate progress on performance indicators that really matter to people who use mental health services. Such systematic analysis is likely to lead to results that support and inform quality improvement, while haphazard efforts and lack of attention to formal measurement of the recovery orientation of local programs and systems may lead to little in the way of real and relevant change.

The ROSI measures—used alone or in conjunction with other tools that are being designed to assess the processes and outcomes of recovery, including complementary efforts to measure the process of recovery at the individual level—can improve the potential for successful assessment of efforts to transform programs and systems. The ROSI measures provide a way to create recovery-oriented programs that are truly consumer driven.

The ROSI measures can be used in the following ways as tools in system transformation:

1. The ROSI measures can be used to create a baseline data set to assess the current status of the recovery orientation of a local program or system. A planning group could use such data to formulate a strategic plan to guide their systems change efforts.
2. The ROSI measures can be used to set specific benchmarks that target desired increments of progress toward a recovery orientation. ROSI data could be gathered at several points in time to measure ongoing quality improvement. The ROSI measures can provide managers with a means to guide or gauge efforts to improve their agency or system. Specific indicators could be targeted for improvement, or general trends could be tracked to assess increases in recovery orientation over time. The ROSI measures give a system a means to track increases in performance indicators associated with processes that facilitate recovery and to track reductions in indicators that consumers say hinder the potential for personal recovery.
3. The ROSI measures can be used to measure general change over time in the recovery orientation of a program or system by sampling consumers at specified intervals and identifying trends in the data. Research using the ROSI measures could also help measure the impact of specific targeted program or system change efforts. Using the ROSI measures to gather follow-up data after new programming is implemented and comparing the ratings to baseline data could inform program evaluation efforts.
4. The performance of provider agencies can be compared by gathering uniform data on the ROSI measures across a local, regional, or county system. Data from all agencies operating in a local system can be gathered, aggregated, and compared to assess the relative performance of local, county, or regional mental health systems operating across a given state.
5. ROSI data can be used as part of an ongoing process of sensitizing and educating mental health providers about important elements that facilitate or impede mental health recovery.
6. The ROSI measures can be used as part of studies of mental health recovery to develop a better understanding of how agency or system-level performance on key indicators relates to other recovery elements, processes, or outcomes.

The ROSI measures have been carefully and rigorously developed and are grounded in the lived experience of people who use mental health services. The measures provide new means to assess service performance and a way to listen to the voice of consumers. The ROSI measures can be used as tools to transform mental health systems so that recovery becomes an increasing reality for Americans with psychiatric disabilities.

Endnotes

Endnote (1): Phase I Partners and Sponsors

Phase I Research Partners

Arizona Dept of Health Services, Division of Behavioral Health Services

Colorado Mental Health Services

New York State Office of Mental Health

Oklahoma Department of Mental Health and Substance Abuse Services

Rhode Island Department of Mental Health/Mental Retardation

South Carolina Department of Mental Health

Texas Department of Mental Health and Mental Retardation

Utah Division of Mental Health

Washington Department of Social and Health Services, Mental Health Division

Phase I Project Sponsors

Substance Abuse and Mental Health Services Administration (SAMHSA) Center for Mental Health Services (CMHS), Survey and Analysis Branch

Colorado Mental Health Services

Columbia University Center for the Study of Social Work Practice

Human Services Research Institute (HSRI)

Mental Health Empowerment Project

Missouri Institute of Mental Health (MIMH)

Nathan Kline Institute for Psychiatric Research,
Center for Study of Issues in Public Mental Health (CSIPMH)

National Association of State Mental Health Program Directors (NASMHPD),
National Technical Assistance Center (NTAC) and National Research Institute (NRI)

New York State Office of Mental Health (NYSOMH)

Oklahoma Department of Mental Health and Substance Abuse Services

Endnote (2): Further Remarks by A. Kathryn Power

“The [President’s New Freedom Commission] Report challenged our nation to create a mental health care delivery system focused on recovery...one that will help our most vulnerable citizens ‘build resilience to face life’s challenges.’ To achieve this promise, the Report recommended no less than a fundamental transformation of how we view and provide mental health care in America.

“Transformation is an extremely powerful concept, with far reaching implications for people and institutions. Transformation is meant to change the very form and function of the mental health care service delivery system. Transformation is about readiness for change and our willingness to take risks. And not just for those of us who shape our system and provide services...but also for the people we serve. They, too, must be ready to change...and willing to risk...because it is their needs, their expectations, and their potential that should drive transformation.

“What will it take to transform our mental health system? This is what I call the ‘Transformation Equation.’ Transformation will require vision plus belief plus action...multiplied many times over by continuous quality [improvement] to the second power. Why is CQI squared? Because we must continuously ask ourselves if the resources and services we provide are effective and meeting the mark. We must continuously seek to improve. Without these elements, transformation cannot, will not, happen. *Achieving the Promise* has given us the vision. We have to complete the equation with belief...and with action.

“Transformation calls for bold action. It cannot be accomplished through change on the margin, but, instead, through profound changes at the core. These changes lead to new behaviors and new competencies. Thus, in transformation, we look at what we can do now that we were unable to do before.

“Beginning with a series of continuous small steps, transformation is meant to identify, leverage, and even create new underlying principles for the way things are done. With transformation, new sources of power emerge.

“Transformation is ultimately about newness—about pushing the boundaries...about new values, new attitudes, and new beliefs. It is about creating something new within the existing paradigm. It is a readiness to change, and a willingness to risk that compels the pace, scope, and character of transformation.

“Transformation of America’s mental health system will not be easy, nor will it happen overnight. It will require all new rule sets that leverage new ideas. It will require commitment from the Federal government, the States, communities, insurers, researchers, consumers, family members, and public and private- sector providers to work together to bring about a new day, when every adult with serious mental illnesses and every child with serious emotional disturbances can live, work, learn, and participate fully in their communities” (Power, 2004b).

Endnote (3): Further Information on Recovery Measurement Approaches

Measures of Personal or Individual Recovery

The Crisis Hostel Healing Scale (Dumont, 2000) was developed through concept mapping with consumers and providers as part of the federally funded Crisis Hostel Project in New York. The Healing Scale was piloted with 110 people from day treatment and social club services. While pattern matching and factor analysis did not strongly support the constructs in the concept map, the instrument shows strong internal consistency reliability (Alpha 0.89) and test-retest reliability at six months with the nontreatment control group (0.67). The 42-item scale was used with 265 people who were randomly assigned to either a treatment or control group. Significant changes over time were shown for the treatment group (i.e., the group that had access to the hostel).

The Recovery Assessment Scale (Corrigan, Giffort, Rashid, Leary, & Okeke, 1999) was initially developed by analyzing four consumers' stories of recovery. From the concepts identified, 39 items were developed. These were reviewed by a group of 12 consumers, whose feedback was instrumental in the development of the final 41-item scale. This scale was tested with 35 consumers in the University of Chicago Partial Hospitalization program. Test-retest reliability between two administrations 14 days apart was 0.88, and the Alpha was 0.93. Factor analysis revealed the following factors: self-esteem, empowerment, social support, and quality of life. This instrument has since been used in the Consumer Operated Services Project (COSP) with about 1,800 consumer respondents.

The Recovery Measurement Tool (Ralph, 2004) was developed by a group of consumers in Maine who based their work on a model of recovery developed by the Recovery Advisory Group (a group of national consumer leaders and activists). The recovery model used a grid that identified internal (cognitive, emotional, spiritual, physical) and external (activity, self-care, social relations, social supports) aspects of recovery, and provided examples of each of these aspects as they occurred across six phases of recovery (anguish, awakening, insight, action plan, determined commitment to get well, and well-being/empowerment). Survey questions (measurement items) were developed for each of the segments of the matrix—100 items were developed. Review of these items found 9 to be duplicative, so the instrument was reduced to 91 items that deal with all aspects of a person's life in the recovery process. The response set chosen for the instrument ranged from “not at all like me” to “not very much like me” to “somewhat like me,” “quite a bit like me,” and “very much like me.” This instrument has not yet been field tested.

Tools Used to Measure the Recovery Orientation of Programs and Systems

The State of Connecticut has used the Recovery Self-Assessment (RSA) scale developed by staff at the Yale University Program on Recovery and Community Health to assess the recovery orientation of the state's mental health provider agencies. The purpose of the RSA is to address the application of recovery principles to reforms in practice and to gauge the degree to which programs implement recovery-oriented practice from the perspective of stakeholder groups.

The development of the RSA began with the development of an initial pool of 80 items that were associated with nine principles of recovery that had been abstracted from consumer, provider,

researcher, and advocate literature on the topic of recovery from psychiatric disorder. Multiple perspectives were attained from stakeholder groups that included agency directors, service providers, persons in recovery, and family members/significant others/advocates. A pilot test was conducted in 10 Connecticut mental health centers, with a total of 122 respondents representing the various stakeholder groups. The RSA was revised and data were collected from stakeholders from all 208 Connecticut mental health provider agencies on a final 39-item measure. A total of 972 stakeholders responded from 78 agencies.

A factor analysis on the statewide data revealed five factors: (1) life goals; (2) consumer involvement; (3) diversity of treatment options; (4) client choice; and (5) individually tailored services. Individual data were aggregated to the level of the agency and an agency recovery profile was generated for each organization. These reports provide the agencies with comparisons to statewide means for all agencies; identify the agencies' strengths (highest rated items) and areas that need improvement (lowest rated items); and suggest targeted improvements. For more information on the RSA, contact Maria O'Connell at <maria.oconnell@yale.edu>.

Assessing Personal Recovery and the Recovery Orientation of Programs and Systems

The Recovery Enhancing Environment (REE) measure assesses personal recovery and the recovery orientation of mental health programs. To assess personal recovery, service users identify their stage of recovery and the markers of recovery (intermediate outcomes) they are currently experiencing. Respondents rate the importance of 24 elements of recovery, including hope, symptom management, wellness, rights, community involvement, meaningful activities, normal social roles, positive relationships, peer support, and others.

To assess the recovery orientation of the program, service users rate the program/staff on three specific behaviors/services that support each of the recovery elements, and on several qualities that have been found to enhance the potential for resilience, such as the presence of caring and compassionate helpers and opportunities for meaningful participation and contribution. People who experience dual diagnoses, trauma survivors, those from minority cultural backgrounds and sexual orientations, and parents also assess the degree to which the program meets their needs. Open-ended questions invite people to share their recovery wisdom and advise staff on how to help people in recovery.

Kansas consumers piloted the measure, and more than 500 people completed the REE in two field tests in Kansas and Massachusetts. Statistical analyses indicate that the instrument is psychometrically sound. People can place themselves in a particular stage of recovery; almost all can identify ways that recovery is taking place in their lives; and data can differentiate higher performing from lower performing programs. The REE is intended to be used in strategic planning, point-in-time or ongoing agency self-assessment, and program evaluation efforts. A user's guide and Microsoft Word and scantron format versions of the REE are available from Priscilla Ridgway, PhD, Program on Recovery and Community Health, Erector Square, Building 6W, Suite 1C, 319 Peck Street, New Haven, CT, 06513 or <priscilla.ridgway@yale.edu>.

Endnote (4): Summary of Phase I Findings: What Helps and What Hinders Recovery?

The major findings of Phase I of the National Study to Create System-Level Recovery Performance Indicators involved the importance of basic material resources; self/whole person; hope/sense of meaning and purpose; choice; independence; social relationships; meaningful activities; peer support; and formal services/staff. The Phase I research revealed that while recovery is a deeply personal journey that is unique for each individual, there are many commonalities in peoples' experience of recovery and a convergence in opinions about what factors tend to facilitate or hold back the process.

Basic Resources and Recovery

Recovery is facilitated by having a set of basic material resources and is held back by the lack of fulfillment of basic material needs. A livable income, safe and decent housing, health care, transportation, and a means of communication (e.g., telephone) all move people toward recovery. Poverty and the lack of basic resources undermine the sense of safety and hold people back in their recovery.

The Social Dimension of Recovery

Recovery involves a social dimension. It is facilitated by having active, interdependent social relationships and being connected to others—including one's family, friends, peers, neighbors, and coworkers—in mutually supportive and beneficial ways. Social and personal isolation, poverty, controlling or demeaning relationships, emotional withdrawal, poor social skills, immigrant status, disabling health and mental health conditions, past trauma, and social stigma impede the social aspects of the recovery journey.

The social dimension expands beyond personal relationships. People indicated that their recovery is enhanced by engaging in meaningful activities that connect them to the larger community. Such connections can be achieved through a meaningful job or career, which often provides a sense of identity and mastery. Participants identified other factors—such as advancing one's education, volunteering, engaging in artistic expression, and group advocacy efforts (such as being involved in program design and policy level decision making)—as moving them forward on their recovery journey. However, participants reported that they experience high rates of unemployment, are often underemployed, and sometimes feel exploited in their work or advocacy efforts. Training and educational opportunities are often lacking; benefit programs include disincentives for returning to work; prejudice and discrimination hamper educational and employment opportunities and can lead to unfair firing; and individual preferences and decisions are often disregarded in terms of engaging in meaningful activities.

Personhood, Self-Agency, and Recovery

The study found “personhood” to be a critical dimension of recovery. Participants in the focus groups talked about the internal sense of self, inner strivings, and the strong desire to be seen as a whole person rather than as a psychiatric label or diagnosis. They described various personal qualities, attitudes, and conditions that help them move forward in recovery, including self-reliance, personal resourcefulness; self-care, self-determination, self-advocacy, self-respect, and a

holistic view of self (seeing oneself or being seen as a physical, emotional, mental, social, and spiritual being). The personhood dimension also involved important elements of hope and optimism, as well as having a sense of purpose and faith, and actively creating meaning in one's life. Focus group participants said that recovery is supported by having goals and options, positive role models of people who successfully contend with psychiatric problems, friendships that are accepting and based on positive interests, and positive personal experiences.

Some aspects of the self can hinder the process of recovery. These include not taking personal responsibility; strong feelings of shame, fear, or self-loathing; invalidation of one's being by others; having one's dreams or preferences demeaned; having one's spirituality, intelligence, or strengths discounted; encountering pessimistic staff and receiving poor quality mental health services; living in poverty; experiencing long-term psychiatric hospitalization; and dealing with a lack of education and information about one's condition and the potential for recovery. These factors can destroy hope and act as roadblocks to personal recovery, and have powerful negative effects on a person's self-concept, self-esteem, and sense of self-efficacy. They are compounded by disabling conditions or symptoms of mental disorder and associated internalized and external stigma, prejudice, and discrimination.

On the other hand, believing that recovery is possible and having this belief supported by others (friends, family, peers, and staff) fuel a positive sense of self-agency. Having access to relevant, accurate information is critical in promoting recovery. Participants want to understand what they are experiencing; they want to be educated and actively participate in making important choices.

Certain cultural affiliations (such as family before self or being a part of a tribal community) may alter the generally strong emphasis on individuality, personhood, and self-agency. Some people focus on kinship and tribal affiliation, interdependency, and the importance of living for the good of their family, clan, or larger social group rather than holding individuality and personal striving as a core value.

Choice and Empowerment

Choice and empowerment are critical dimensions of recovery. Recovery is promoted when people gain power and control over their lives, and when they have access to meaningful choices and the resources they need to implement those choices. Having information on, access to, and a range of meaningful, desirable, and useful options fosters recovery. Participants are empowered when they can make meaningful choices regarding where they live, their finances, employment, personal living/daily routine, the disclosure of information, and whom they associate with, and when treatment options encourage self-management of their condition. Meaningful options must exist, along with training and support in making choices, and people must have the freedom to take risks and learn from personal experience. Individual participants talked about the empowering experience of choosing how one sees oneself, one's disorder, one's situation, and one's quality of life.

Many participants said a decent quality of life and real options too often seem to be outside their reach; that their options seemed limited, lousy, or nonexistent. Participants recounted many instances in which service providers, professionals, family members, and communities used

coercion or threats to control their lives; restricted their access to or involvement in meaningful activities; or responded to their needs in ways that were demeaning or demonstrated prejudice, discrimination, and stigma.

Independence—not being subject to the control of others and not relying too much on others—also falls into the empowerment dimension. Participants described independence as both a process that supports recovery and a goal of the recovery process. Independence is achieved through making one’s own choices and decisions and exercising self-determination (for example, by preparing advance directives that are honored when one is in a crisis). Independence involves enjoying basic civil and human rights and freedoms, and having a set of basic resources such as a livable income, transportation such as a car, affordable housing, and so on.

Paternalistic responses, lack of respect, involuntary and long-term hospitalization, stereotyping, labeling, discrimination, and the risk of losing what few benefits and supports one does have as one recovers—all these can undermine independence and recovery. Multiple negative experiences can instill fear, a lack of confidence, and negative attitudes and beliefs that hinder recovery.

Some participants talked of the importance of both independence and interdependence, while others felt that independence is unrealistic; a positive sense of interdependence was a better goal for some as they move toward recovery. Interdependence implies connection with others; seeking independence and a positive sense of interdependence are not mutually exclusive.

Peer Self-Help

Peer self-help is another critical dimension that supports recovery. This includes peer-operated services, having peer recovery role models, and being involved in the consumer movement, which provides people with opportunities to understand, mutually promote, and achieve recovery. Participants said there was a need for a large-scale expansion, funding, support, and increasing availability of peer support services. Services such as peer support, peer education, peer outreach, recovery role models, peer specialists, peer mentors, and peer advocates, as well as the employment of people with a history of psychiatric disorders at all levels of the mental health service system, support personal recovery. (A follow-up member check asked focus group participants to prioritize the study findings. Self-help and peer support were the most important resources people thought the mental health system should concentrate on to promote recovery.)

The potential of peer support to facilitate recovery is hampered by the lack of peer support services and self-help options, especially in rural areas; limited funding for such options; the low level of participation in peer support; lack of leadership development opportunities; power issues; lack of transportation; and lack of referral to peer support by controlling and mistrustful professionals.

The Formal Service System

The formal service system and the staff employed in that system have an impact on recovery. The research showed that the formal system can support progress toward recovery. Unfortunately, in many cases, staff and other elements of the formal system actually hinder recovery.

Social welfare and mental health systems often hinder recovery by imposing overly bureaucratic program guidelines and limiting access to services and supports. Abusive practices, poor quality services, the promotion of negative messages such as hopelessness, the lack of best practice program elements, and a narrow bio-psychiatric orientation tend to hinder recovery. The bio-psychiatric orientation often does not view the individual as a whole person, discounts the person's full humanity, and ignores the full range of the person's material, psychological, emotional, social, and spiritual needs and strengths.

People have basic subsistence needs that the social safety net may not meet. Social welfare and mental health programs are too fragmented and too difficult to access. Systems often limit help to those in crisis. People do not want to have to deteriorate in order to receive help, nor do they want to lose vital supports when they begin to make progress toward recovery. Psychiatric services are often experienced as a means of social control, which counters individual efforts toward recovery. The experience of trauma and abuse were notable in the focus group data, and systems often are not sensitive to the need to heal trauma and its consequences. They often fail to incorporate trauma sensitive knowledge in explanations of and responses to psychiatric disorder. The fact that service recipients often have little social status is clear in the study findings. People internalize the social stigma they feel in the mental health system; the system often repeatedly re-traumatizes people, and the trauma of past abuse in the mental health system continues to have a negative impact.

Data indicate the need to return to the basic core of helping—the development of a positive helping relationship or “therapeutic alliance” based on partnership. Participants want to have people care about them, respect them, listen to them, and empower them. They want the helping relationship to promote self-determination and choice. People do not want to interact with neutral, detached helpers, nor do they want to meet a new professional or paraprofessional each time they seek help. People want the opportunity to express their preferences, needs, and choices to their helpers and to build a partnership with their doctor, therapist, or case manager. People want to work collaboratively to develop an individual treatment plan, and they want full information on the potential benefits and side effects of treatment options, including medications. They want to be in charge of their treatment or recovery plans to the maximum degree possible, and they want to exercise choice in all aspects of their lives, including having a mental health care proxy or advance directive that will be followed if they experience a crisis or setback.

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Appendices

Appendix A: National Project Dissemination Activities (Updated: March 2005)

Appendix B: Self-Report Item Reading Level Comparison

Appendix C: Phase II Self-Report Prototype Test Demographics

Appendix D: Phase II Self-Report Prototype Test Item Response Results

Appendix E: Phase II Self-Report Prototype Test Item Importance Rating

Appendix F: Phase II Self-Report Prototype Test Item Reduction Results

Appendix G: ROSI Consumer Self-Report Survey

Appendix H: ROSI 10-Item Self-Report Subset

Appendix I: Phase II Administrative-Based Item Survey Results

Appendix J: ROSI Administrative Data Profile

Appendix K: ROSI Pilot Information, Guidelines and Process Form

**Appendix A:
National Project Dissemination Activities
(Updated: May 2005)**

Appendix A: National Project Dissemination Activities (Updated: May 2005)

Reports

Onken, S.J., Dumont, J.M., Ridgway, P., Dornan, D.H., & Ralph, R.O. (2002, October). *Mental Health Recovery: What Helps and What Hinders? A National Research Project for the Development of Recovery Facilitating System Performance Indicators. Phase One Research Report: A National Study of Consumer Perspectives on What Helps and Hinders Mental Health Recovery*. National Association of State Mental Health Program Directors (NASMHPD) National Technical Assistance Center (NTAC), Alexandria, VA.

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Onken, S. J., Dumont, J. M., Ridgway, P., Dornan, D. H., & Ralph, R. O. (2003, Winter/Spring). Mental health recovery: What helps and what hinders? *Balance, the Journal of the Mental Health Association Queensland, Inc.*, 27–31 (Australia).

Presentations Completed

Onken, S.J. & Ashenden, P. *The Person in Recovery Derived Recovery Oriented System Indicators Measure (ROSI): Development and Use*. Institute, 30th Annual USpra Conference, Pittsburgh, PA, May, 2005.

Onken, S.J. *ROSI: The Recovery Oriented System Indicators Measure*. General Session, CMHS Data Infrastructure Grant (DIG) Annual Meeting, Baltimore MD, February, 2005.

Dornan, D.H., Ashenden, P. & Onken, S.J. *Introducing ROSI: Consumer Derived Recovery Oriented System Indicators Measure*. Workshop, Alternatives 2004: Achieving the Promise of Recovery, Denver CO, October 2004.

Townsend, W., Hopkins, G., Ridgway, P., Onken, S.J., & Veierstahler, A.C. *Achieving Lasting recovery: Reality and Measurement*. Plenary, 2004 Joint National Conference on Mental Health Block Grant and Mental Health Statistics, Washington, DC, June 2004.

Onken, S.J. *User Perspectives on Mental Health Recovery Facilitating and Hindering Factors*. Paper, The Fourth International Conference on Social Work in Health and Mental Health, Québec City, Canada, May 2004.

Onken, S.J. *A Recovery Oriented System: What It Is, What It Isn't, Our Challenges and Opportunities*. Concurrent Session, The Rights and Empowerment Conference, Research Triangle Park, North Carolina, May 2004.

Onken, S.J. *Introducing ROSI: The Recovery Oriented System Indicators Measure*. Plenary, The 4th Annual Mental Health Performance Indicator and Outcomes (PIO) Conference, Denver CO, April 2004.

Onken, S.J., & Ridgway, P. *What Helps and What Hinders Mental Health Recovery? Consumer Perspective Results of the National Research Project for the Development of Recovery Facilitating System Performance Indicators*. Paper, 8th Annual Conference of the Society for Social Work Research, New Orleans, LA, January 2004.

Onken, S.J., Ridgway, P., Townsend, W., & Hopkins, G. *A Recovery Oriented System and its Measurement*. Plenary, 2003 Joint National Conferences on Mental Health Block Grant and Mental Health Statistics, Washington DC, May 2003.

Ridgway, P. *What Helps and What Hinders Recovery within the Social Environment: Including the Mental Health System*. Workshop, 2003 International Association of Psychosocial Rehabilitation Services Annual Meeting, Atlanta GA, May 2003.

Rivera, M. *Mental Health Recovery: What Helps and What Hinders? A National Research Project for the Development of Recovery Facilitating System Performance Indicators*. Plenary, Colorado 3rd Annual Mental Health Performance Indicator and Outcomes Conference, Denver CO, April 2003.

Onken, S.J. *Mental Health Recovery: What Helps and What Hinders? An USA National Research Project for the Development of Recovery Facilitating System Performance Indicators*. Paper, World Federation for Mental Health Biennial Congress, Melbourne Australia, February 2003.

Robin, C., Knight, E., Bush, B., Alexander, M.J., & Onken, S.J. *Factors Promoting Recovery: A Holistic Approach to Service Systems Change*. Panel Presentation, 13th Annual Conference on State Mental Health Agency Services Research, Program Evaluation and Policy, Baltimore MD, February 2003.

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Onken, S.J. *Mental Health Recovery: What Helps and What Hinders? A National Research Project for the Development of Recovery Facilitating System Performance Indicators*. Paper, Fifth Annual International Inter-Centre Network for Evaluation of Social Work Practice Workshop, Columbia University, New York NY, October 2002.

Dumont, J.M. & Ridgway, P. *Mental Health Recovery: What Helps and What Hinders?* Breakout Session, 44th Annual Southern Regional Conference on Mental Health Statistics, New Orleans LA, September 2002.

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Ridgway, P. *What Helps and What Hinders Recovery?* The Adult Systems of Care Partnership Conference "Thinking Outside the Box," San Mateo CA, September 2002.

Onken, S.J., Dumont, J. M. & Ridgway, P. *Mental Health Recovery: What Helps and What Hinders? A National Research Project for the Development of Recovery Facilitating System Performance Indicators*. Concurrent Session, 51st Annual National Conference on Mental Health Statistics, Washington D.C., May 2002.

Onken, S.J. *Mental Health Recovery: What Helps and What Hinders? A National Research Project for the Development of Recovery Facilitating System Performance Indicators*. Invited Speaker, National Association of State Mental Health Program Directors, Alexandria VA, April 2002.

Onken, S. J. *Recovery and Consumer Involvement*. Plenary, Colorado Mental Health Services Conference on Evaluating Mental Health Performance, Denver CO, April 2002.

Onken, S. J. *New Developments in MHSIP: The National Research Project for the Development of Recovery Facilitating System Performance Indicators*. Plenary Panel, 50th Annual National Conference on Mental Health Statistics, Washington D.C., May 2001.

Internet Postings

Measuring Recovery at the System Level: Consumer Self-Report Survey and Administrative-Data Profile. In *NASMHPD/NTAC e-Report on Recovery*, Fall 2004, a posting of the National Association of State Mental Health Program Directors (NASMHPD) and the National Technical Assistance Center for State Mental Health Planning (NTAC).

Measuring System Impacts on Mental Health Recovery: First Results from a National Research Project (February 2003). In *Evaluation FastFacts 2(2)*, a posting of the Evaluation Center@HSRI.

Announcement and executive summary of Phase One Research Report on Mental Health Recovery: What Helps and What Hinders? (October 31 2002). In *Mental Health E-News*, a posting of the New York Association of Psychiatric Rehabilitation Services.

Other Distribution

OMH Contributing to National Research Project on Recovery. *OMH Quarterly*, March 2003, New York State Office of Mental Health newsletter.

New York State Office of Mental Health's 15th Annual Research Conference, Albany NY, December 2002, Phase One Research Report announcement.

Science-to-Services Institute on Adult Mental health Evidence-Based Practices, St. Petersburg FL, November 2002, Executive Summary of Phase One Research Report included in handout notebook.

National Study on System Performance Indicators, *Conference Update* 2(35), November 8 2002,
New York State Conference of Local Mental Hygiene Directors newsletter.

Appendix B:
Self-Report Item Reading Level Comparison

Appendix B: Self-Report Item Reading Level Comparison

Think aloud Set	Prototype Set
1. I have work opportunities that are meaningful to me.	1. I have paid work opportunities that are meaningful to me.
2. Mental health services provided the assistance I needed in getting or keeping employment.	2. Mental health services helped me get or keep employment.
3. I have opportunities to advance my education.	3. I have a chance to advance my education if I want to.
4. Mental health services provided the assistance I needed in advancing my education.	4. Mental health services helped me in advancing my education if I wanted to.
5. I have affordable housing.	5. I have housing that I can afford.
6. Mental health services provided the assistance I needed in getting affordable housing.	6. Mental health services helped me get housing that I can afford.
7. I have reliable transportation when I need it.	7. I have reliable transportation to get where I need to go.
8. Mental health services provided the assistance I needed in getting reliable transportation.	8. Mental health services helped me get reliable transportation.
9. I have an income I could live on.	9. I have enough income to live on.
10. Mental health services provided the assistance I needed in obtaining a livable income.	10. Mental health services helped me obtain enough income to live on.
11. I have housing in a safe location.	11. I live in a safe location.
12. Mental health services provided the assistance I needed in getting housing in a safe location.	12. Mental health services helped me get housing in a place I feel safe.
13. I have inadequate medical benefits (for example, no dental care, no eye care, no choice in doctors, etc.).	13. My medical benefits do not meet my needs (for example, no dental care, no eye care, no choice in doctors, limited prescriptions, etc.).
14. Mental health services provided the assistance I needed in getting adequate medical benefits.	14. Mental health services helped me get medical benefits that meet my needs.
15. There was a peer advocate to turn to when I needed one.	15. There was a consumer peer advocate to turn to when I needed one.
16. There were peers working as paid employees in the mental health services I received.	16. There are consumers working as paid employees in the mental health agency where I receive services.
17. I found helpful services in peer run programs that were not available in traditional mental health services.	17. I found helpful services in consumer run programs that were not available in other mental health services.

Think aloud Set	Prototype Set
18. Staff supported my right to take a risk or make a mistake.	18. Staff supports my right to try new things, take a risk or make a mistake.
19. I had a say in what happened to me when I was in crisis.	19. I have a say in what happens to me when I am in crisis.
20. I was provided full information in language I understood before I consented to treatment (including medication).	20. Staff give me complete information in words I understand before I consent to treatment or medication.
21. I had opportunities to do things that are meaningful to me.	21. Staff encourage me to do things that are meaningful to me.
22. Staff provided me information and advocacy on obtaining needed benefits.	22. Staff stood up for me to get the services and resources I needed.
23. Staff understood my cultural background (race, ethnicity, religion, language, age, sexuality, etc).	23. Staff treat me with respect regarding my cultural background (think of race, ethnicity, religion, language, age, sexual orientation, etc).
24. Staff believed that I could grow, change and recover.	24. Staff believe that I can grow, change and recover.
25. Staff listened carefully to what I said.	25. Staff listen carefully to what I say.
26. Staff lacked up-to-date knowledge on the most effective treatments.	26. Staff lack up-to-date knowledge on the most effective treatments.
27. I could have a say in how my service program operates.	27. I can have a say in how my service agency operates.
28. Staff saw me as an equal partner.	28. Staff see me as an equal partner in my treatment program.
29. My treatment plan goals were stated in my own terms.	29. My treatment plan goals are stated in my own words.
30. Mental health services interfered with my personal relationships.	30. Mental health staff interfere with my personal relationships.
31. Mental health services helped me build on my strengths.	31. Mental health staff help me build on my strengths.
32. I was supported by mental health staff in my self care or wellness.	32. Mental health staff support my self-care or wellness.
33. I had access to alternatives to hospitalization and/or involuntary treatment.	33. Staff help me stay out of psychiatric hospitals and avoid involuntary treatment.
34. My right to refuse treatment was respected.	34. My right to refuse treatment is respected.
35. Treatment or medication was forced on me.	35. Treatment or medication was forced on me.
36. Staff controlled me through pressure, threats or force.	36. Staff use pressure, threats, or force in my treatment.
37. Staff respected my wishes about who was and who was not to be given information about my treatment.	37. Staff respect my wishes about who is and who is not given information about my treatment.

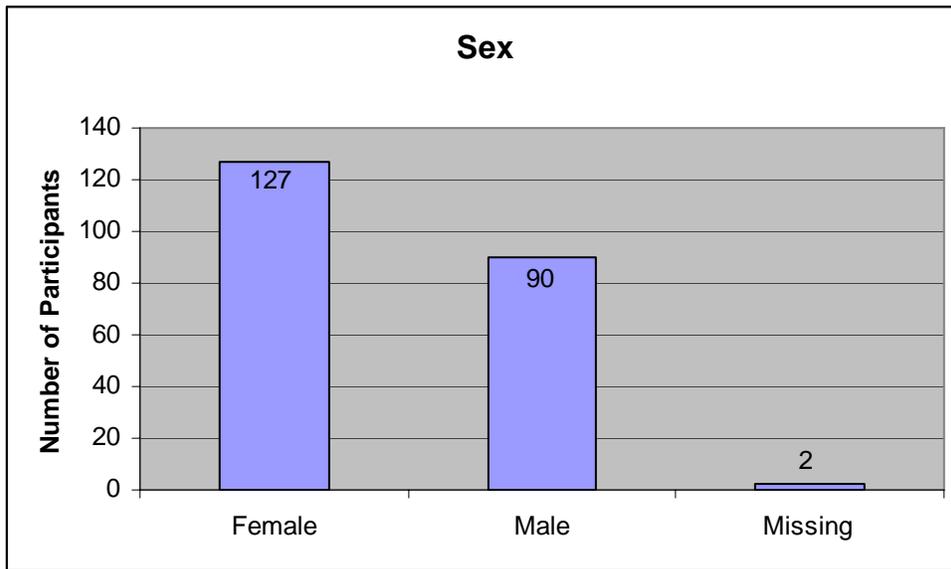
Think aloud Set	Prototype Set
38. The time I had with my psychiatrist was too brief to be helpful.	38. The time I have with my psychiatrist is too brief to be helpful.
39. There was too much turn over in my mental health providers.	39. There are too many changes in the staff who provide my services.
40. I had access to medications that worked best for me.	40. The doctor worked with me to get on medications that were most helpful for me.
41. I had information or guidance to get the services I needed.	41. I have information or guidance to get the services and supports I need, both inside and outside my mental health agency.
42. I could get combined services and supports for both substance abuse and mental illness.	42. I can get combined services and supports for both substance abuse and mental illness.
43. I could see a therapist when I needed to.	43. I can see a therapist when I need to.
44. My family got the education and/or supports they needed to be helpful to me.	44. My family gets the education or supports they need to be helpful to me.
45. I was given information about medication side effects in language I understood.	45. I am given information about medication side effects in words I understand.
46. I was viewed as a psychiatric label rather than a person.	46. I am treated as a psychiatric label rather than as a person.
47. I had access to peer role models.	47. I have access to other consumers who act as role models.
48. I was encouraged to use consumer-run programs (support groups, drop-in centers, crisis phone lines, etc.).	48. I am encouraged to use consumer-run programs (for example, support groups, drop-in centers, etc.).
49. I did not have enough service options to make good choices.	49. I do not have enough good service options to choose from.
50. I was not free to associate with people of my choice.	50. Service programs restrict my freedom to associate with people of my choice.
51. I had a place to live that felt like home to me.	51. I have a place to live that feels like a comfortable home to me.
52. Staff respected me as a whole person.	52. Staff respect me as a whole person.
53. Staff treated me as though I would never function well.	53. Staff treat me as though I will never be able to function well.
54. Staff did not understand my experience as a person with mental health problems.	54. Staff do not understand my experience as a person with mental health problems.

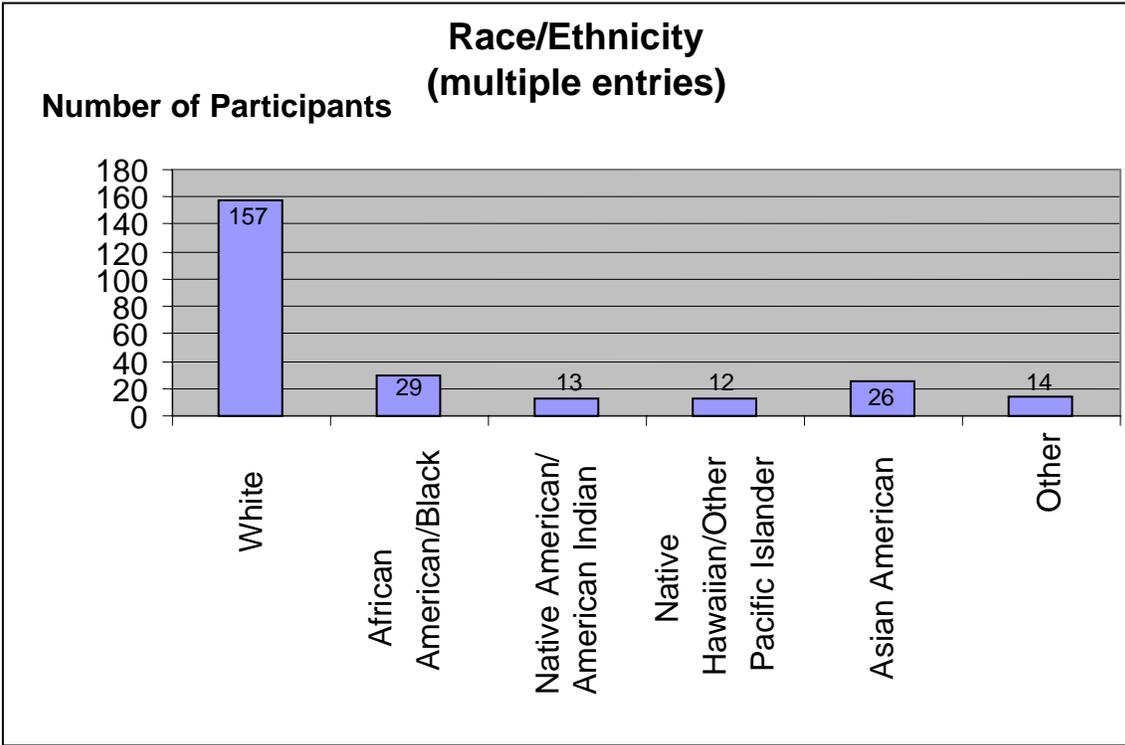
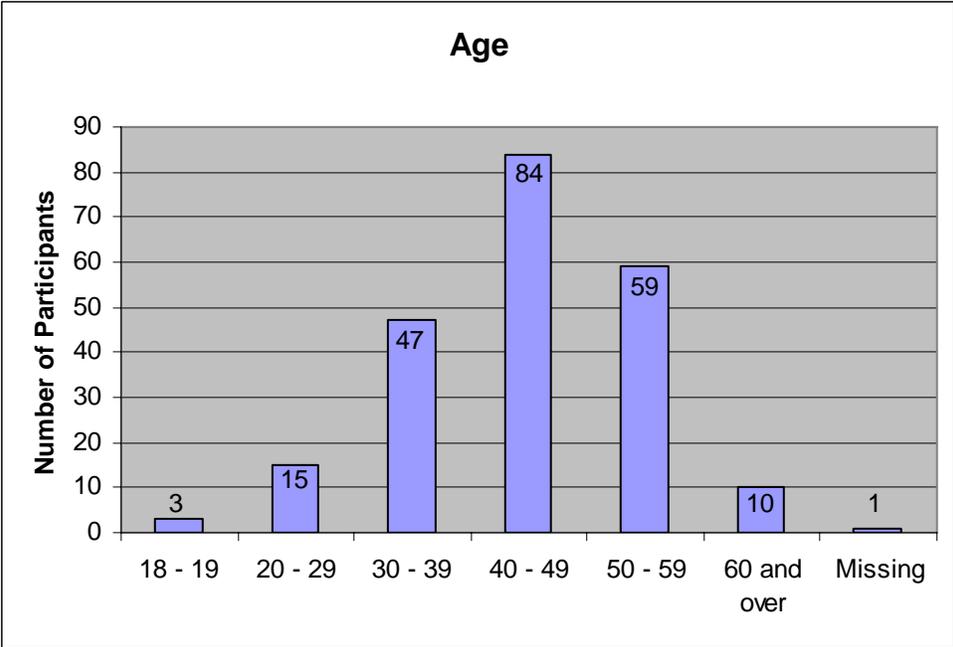
Think aloud Set	Prototype Set
55. I received support as a parent for my children and myself.	55. I receive support to parent my children.
56. There was at least one person who believed in me.	56. There is at least one person who believes in me.
57. I had supports to develop friendships with people outside the mental health system.	57. I have supports to develop friendships with people outside the mental health system.
58. I did not have the support I needed to function in the roles I want in my community.	58. I do not have the support I need to function in the roles I want in my community.
59. I had help in exploring resources to develop my spiritual growth, when I wanted such help.	59. I have help in exploring resources for my spiritual growth, when I want such help.
60. The mental health staff ignored my physical health.	60. The mental health staff ignore my physical health.
61. I was afraid that if I did too well I'd lose my supports and services.	61. I am afraid that if I do too well I will lose my supports and services.
62. Grievances about mental health services were respectfully resolved.	62. Complaints or grievances about mental health services were respectfully resolved.
63. Services were not designed to meet my changing needs.	63. Services are not flexible to meet my changing needs.
64. Mental health services have emotionally or physically harmed me.	64. Mental health services have caused me emotional or physical harm.
65. I had access to specialized trauma services as needed.	65. I have access to services for trauma or abuse as needed.
66. I could not get the services I needed when I need them.	66. I cannot get the services I need when I need them.
67. Staff encouraged me to take responsibility for how I live my life.	67. Staff encourage me to take responsibility for how I live my life.
68. Services helped me develop the skills I needed.	68. Services help me develop the skills I need.
69. I had assistance to create an advanced directive.	69. I have help in creating a plan for how I want to be treated in the event of a crisis, such as an advance directive.
70. My mental health services created dependence, not independence.	70. Mental health services led me to be more dependent, not independent.
71. Mental health services fed into negative feelings about myself.	71. Mental health services fed into my negative feelings about myself.
72. I lacked the information I needed to uphold my rights.	72. I lack the information or resources I need to uphold my client rights and basic human rights.
73. I had support for challenging negative stereotypes and/or discrimination if I needed it.	73. I have support for challenging negative stereotypes, stigma and/or discrimination.

Appendix C:
Phase II Self-Report Prototype Test Demographics

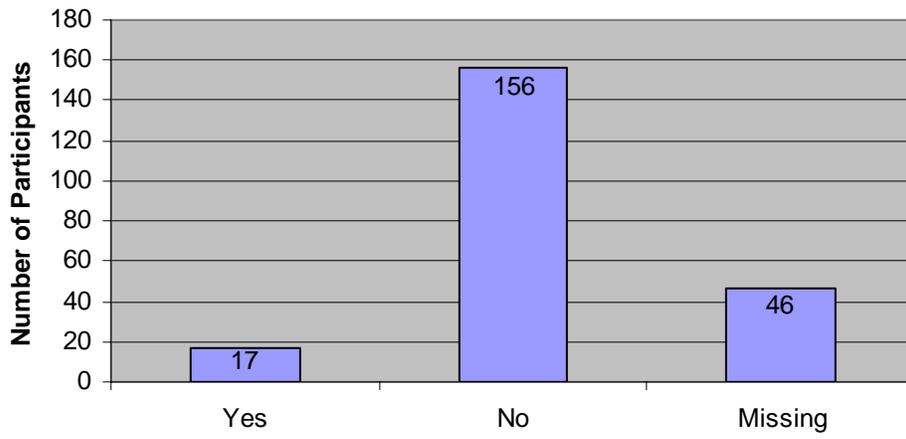
Appendix C: Phase II Self-Report Prototype Test Demographics

Phase Two surveys were completed by 219 individuals across seven different US states. Participants reported on 15 demographic items including sex, age, race/ethnicity, community, marital status, parenting status, living situation, income and education level. Participants also provided information regarding mental health, including their psychiatric diagnoses, addiction diagnoses, psychiatric hospitalizations, participation in consumer/survivor organizations, length of time receiving mental health services and current mental health status.

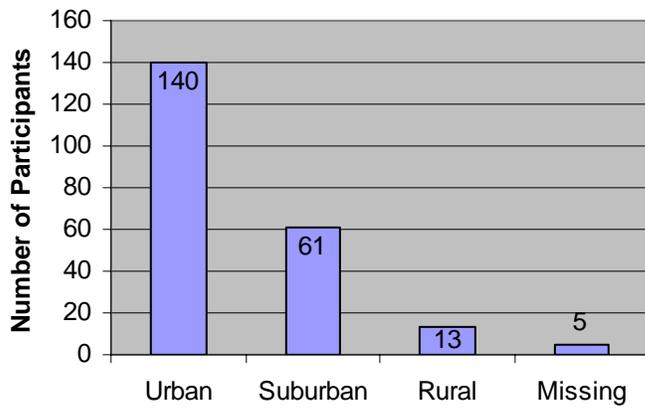


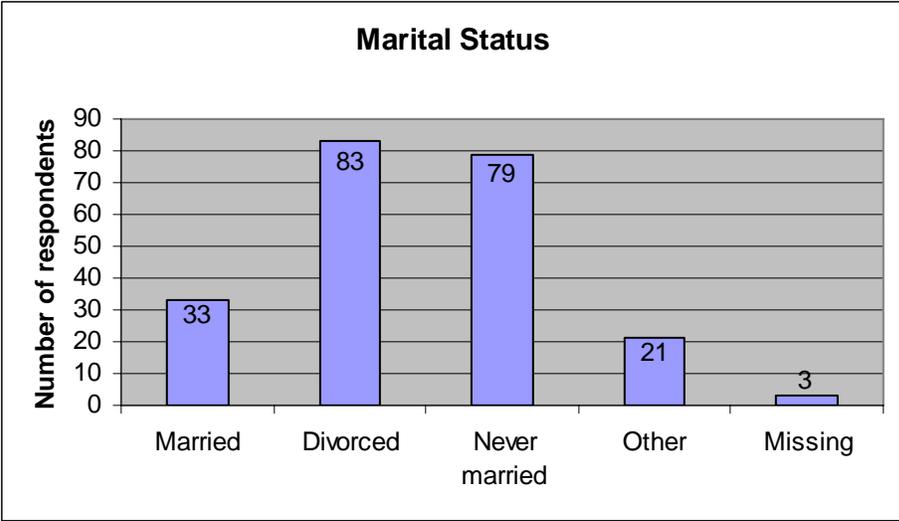


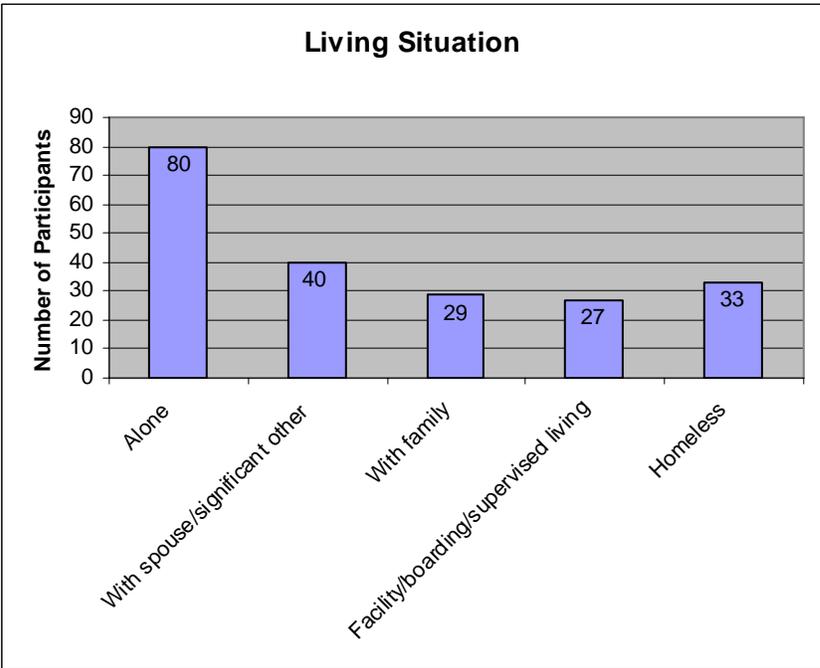
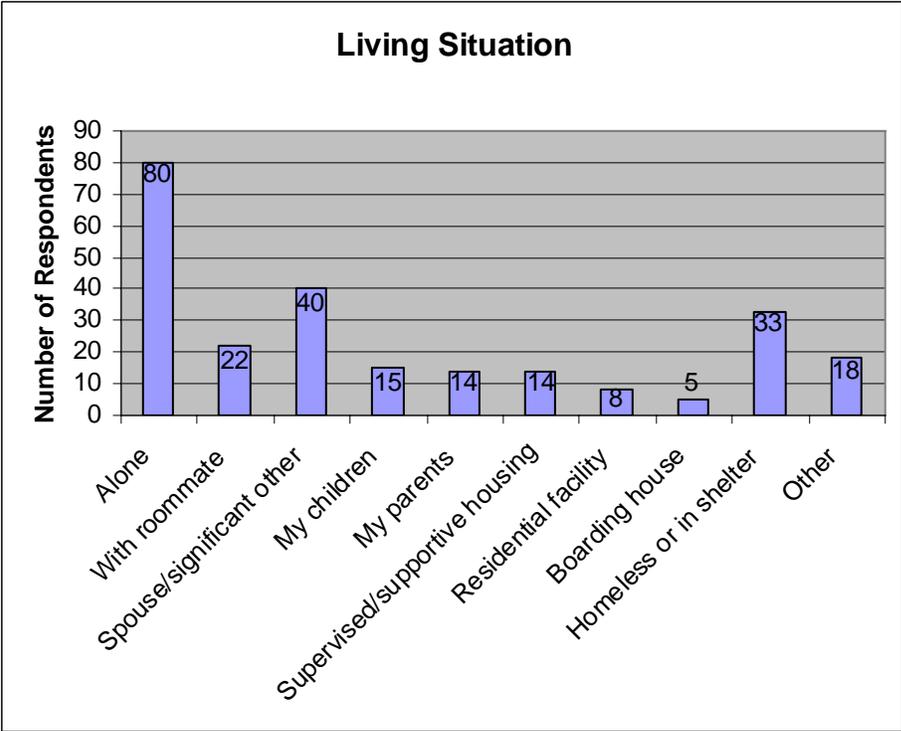
Do you consider yourself Hispanic or Latino/a?

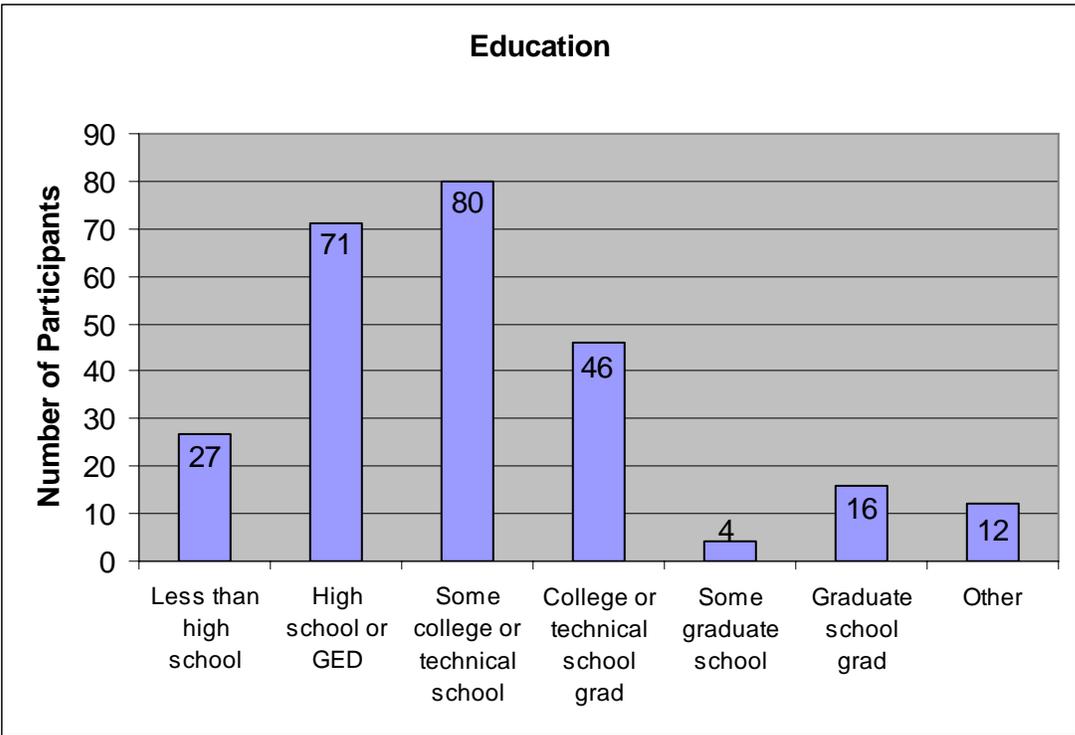
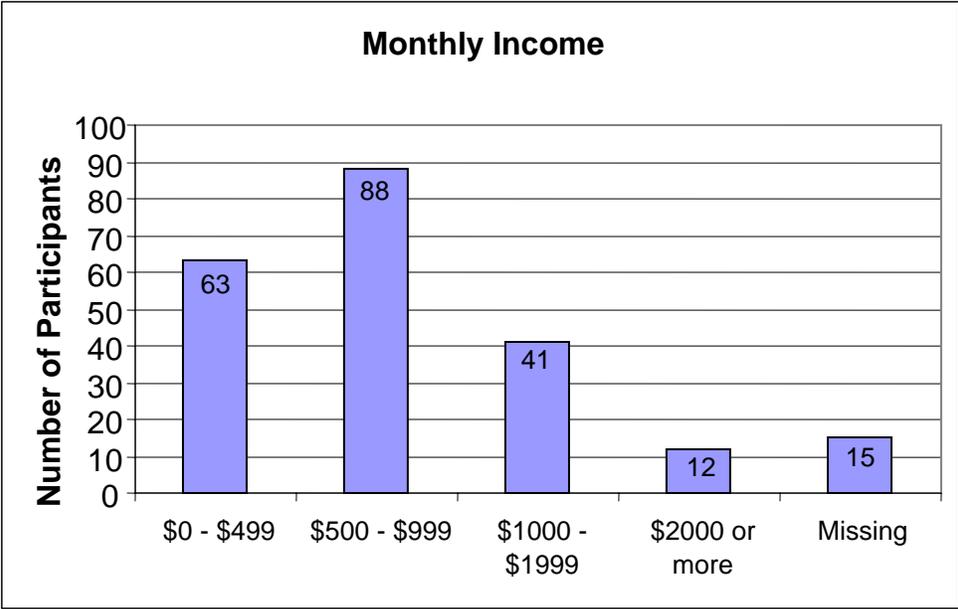


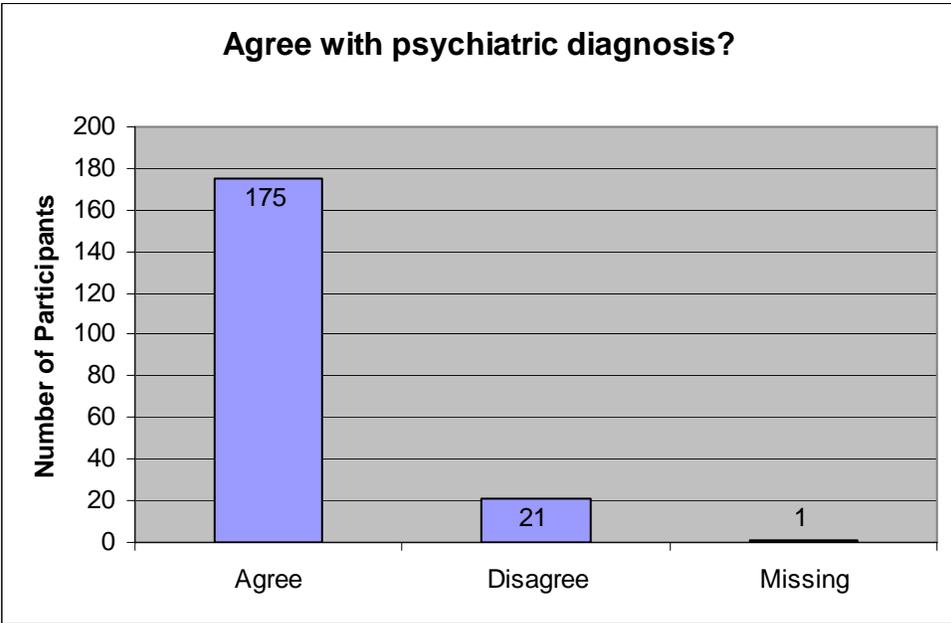
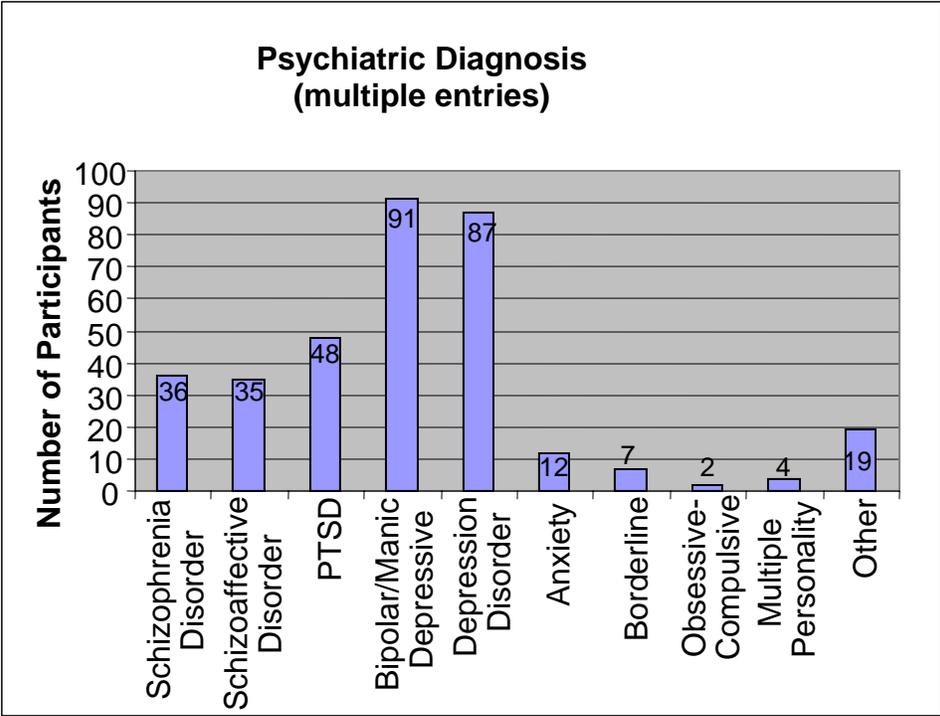
Community

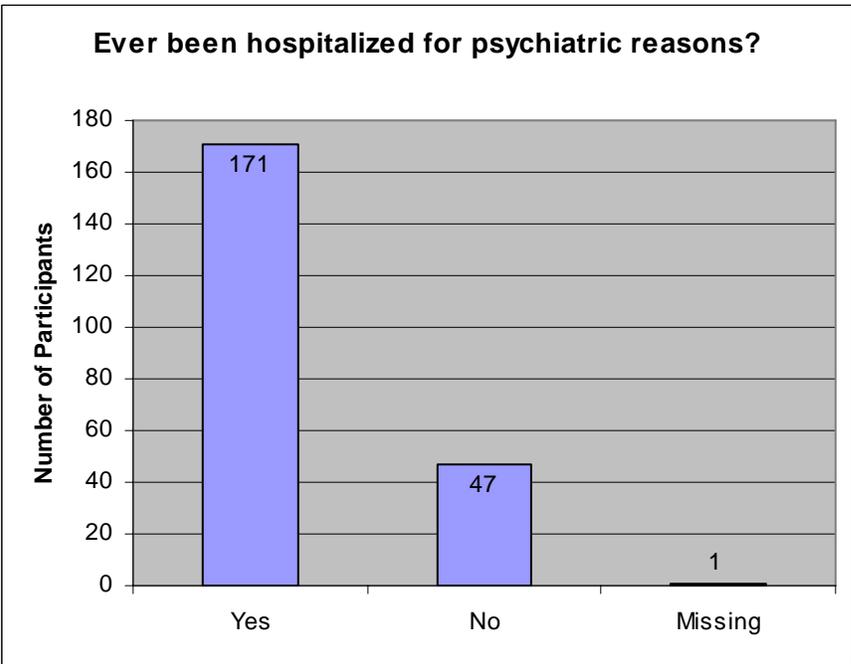
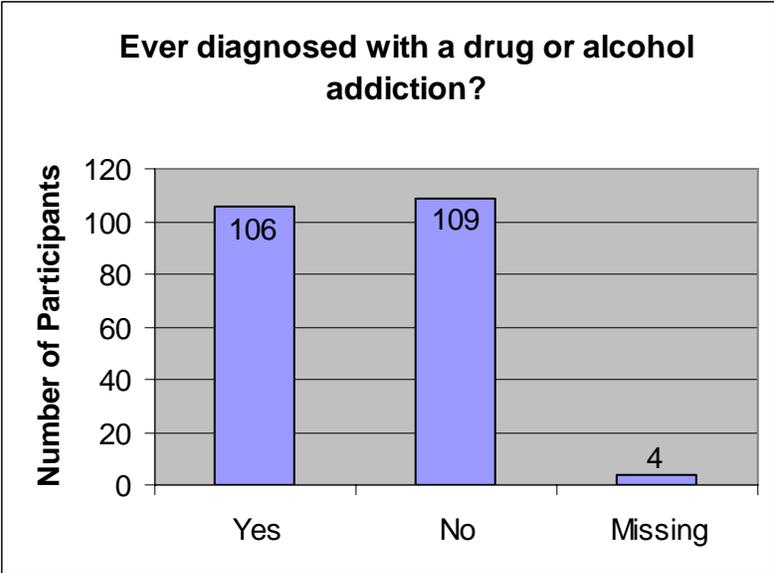


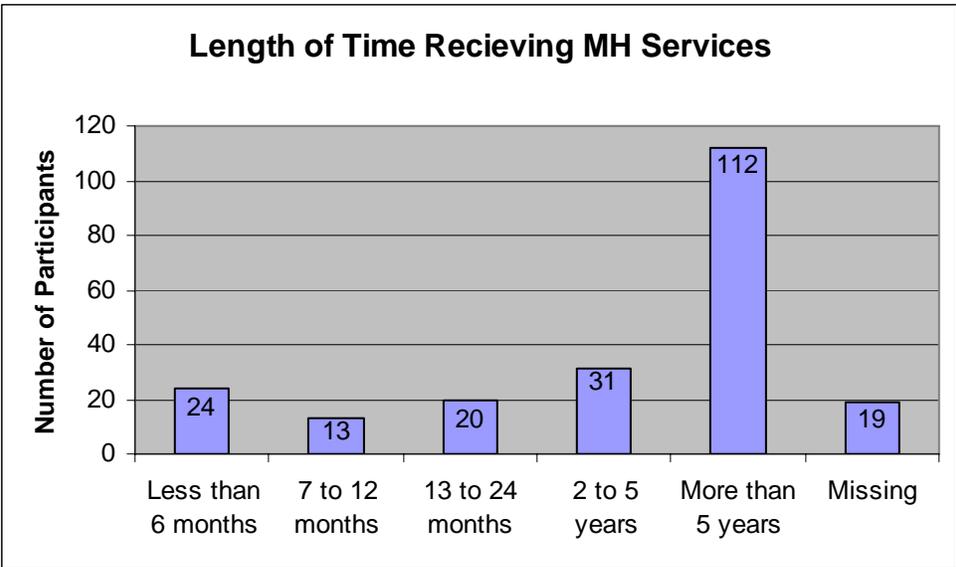
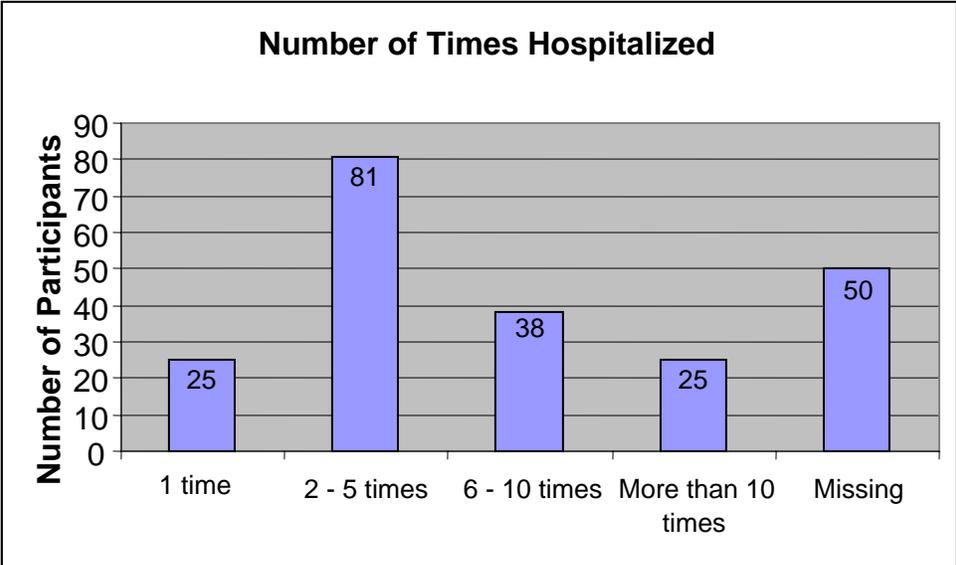


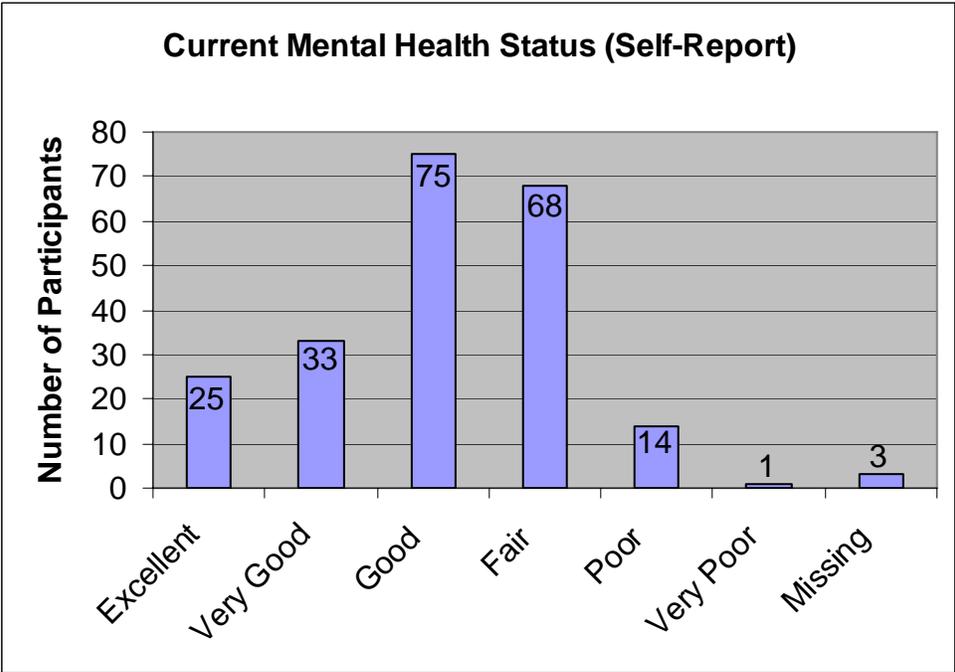
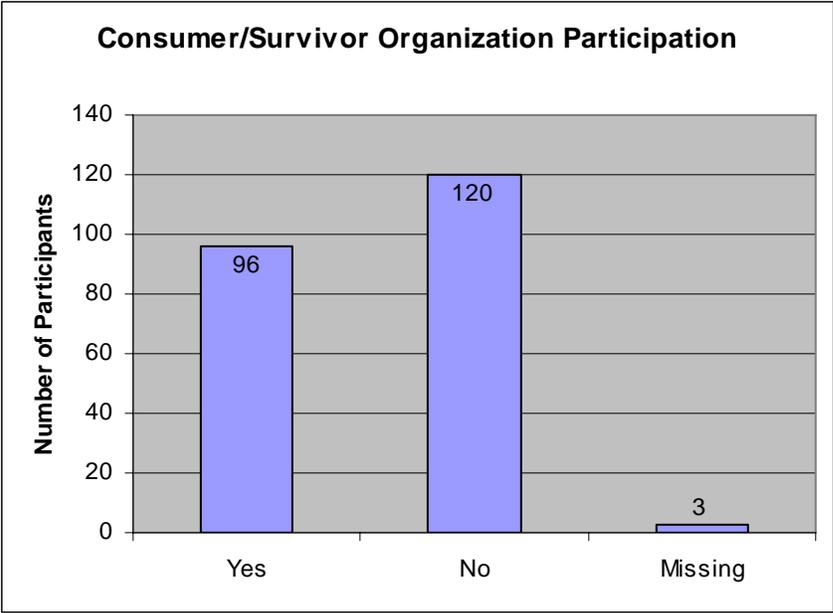












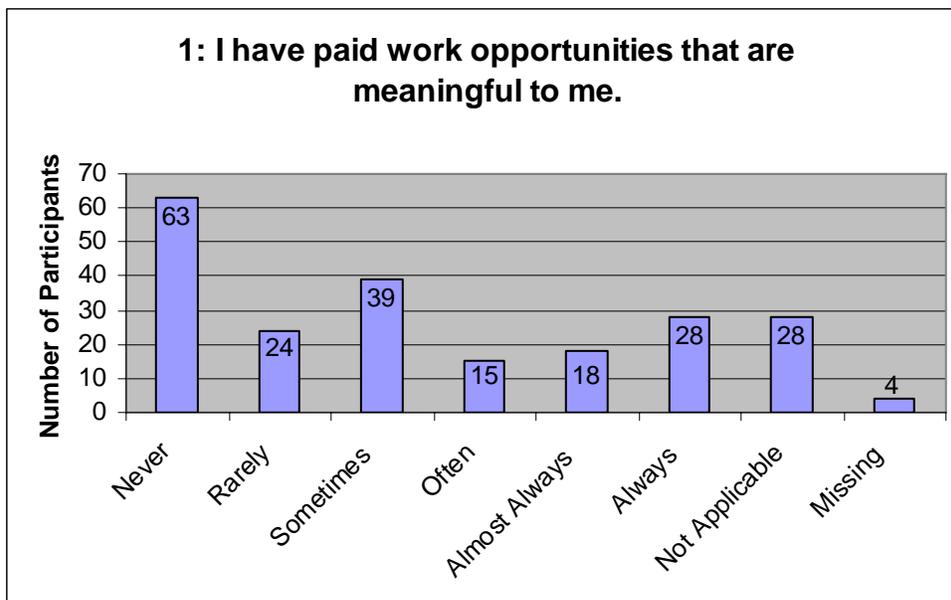
Appendix D:
Phase II Self-Report Prototype Test
Item Response Results

Appendix D: Phase II Self-Report Prototype Test Item Response Results

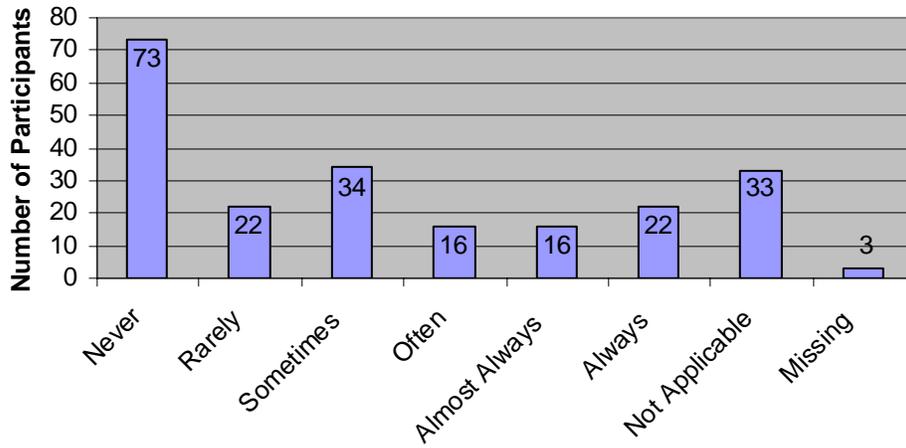
Participants responded to 73 items using two different response scales: one of them a 6-point scale (Never, Rarely, Sometimes, Often, Almost Always, Always) and the other a 4-point scale (Strongly Disagree, Disagree, Agree, Strongly Agree), both with the additional option of responding “Does not apply to me”. For the first 14 items, participants were instructed to respond “in general during the last six months”, while for the remaining 59 items they were instructed to respond regarding “mental health services and staff during the last six months”.

Items were developed to retain as such as possible the wording used by Phase One participants when they described the helping or hindering forces they experienced in their recovery process. To this end, 20 of the 73 items were negatively worded to aid in the ability to gather differentiated responses.

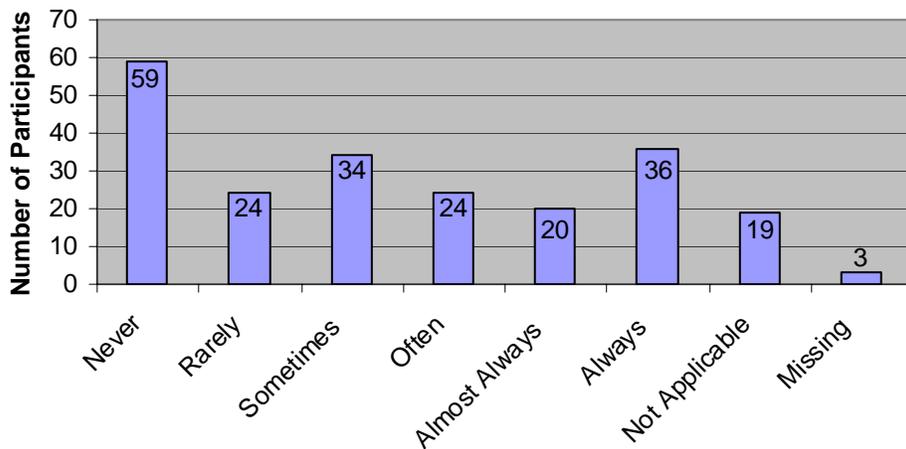
Participants responded to 25 of the items with a wide range of responses across the 4- and 6-point scales (including items 1, 9, 10, 13, 15, 17, 18, 28, 29, 31, 38, 39, 42, 43, 51, 54, 55, 58, 61, 64, 66, 69, 70, 71, and 72). Furthermore, 21 of the items included 30 or more “does not apply to me” responses, with 6 of those including 50 or more such responses. One of these, item 55: “I receive support to parent my children” is clearly aligned with the number of participants who identified themselves as parents.



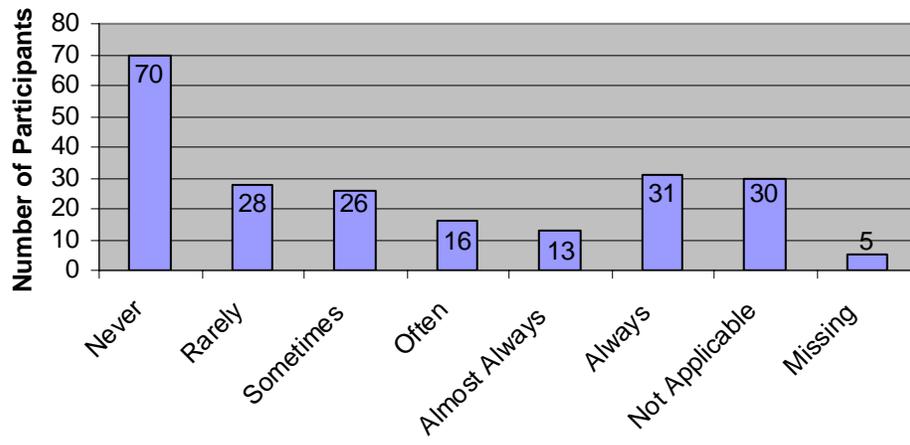
2: Mental health services helped me get or keep employment.



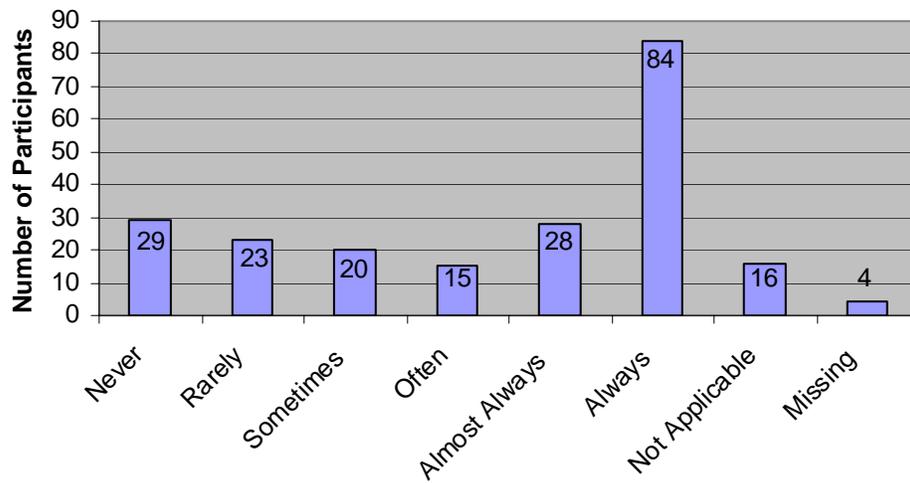
3: I have a chance to advance my education if I want to.



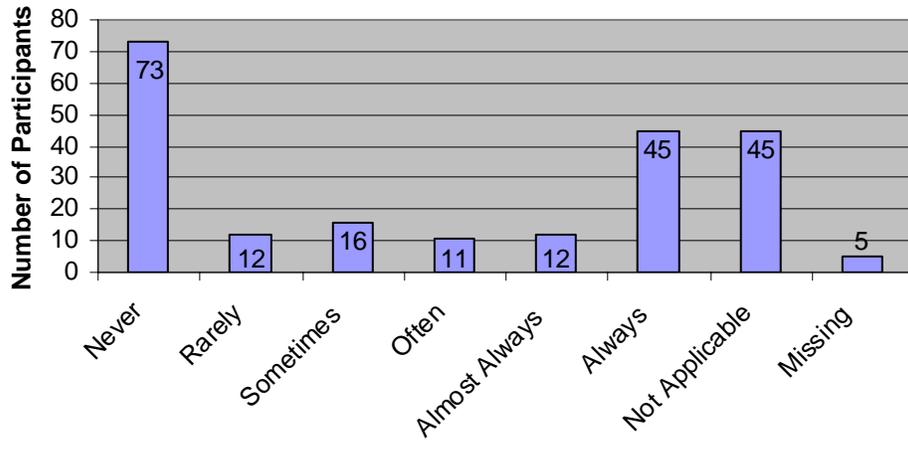
4: Mental health services helped me in advancing my education if I wanted to.



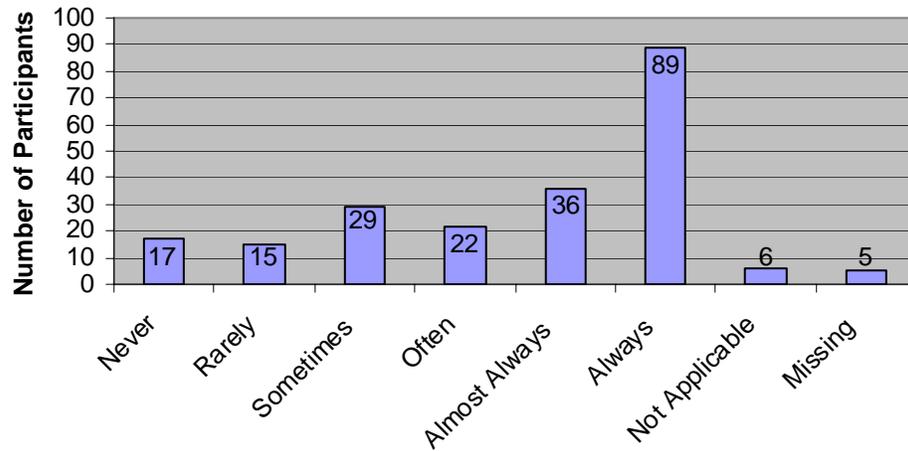
5: I have housing that I can afford.



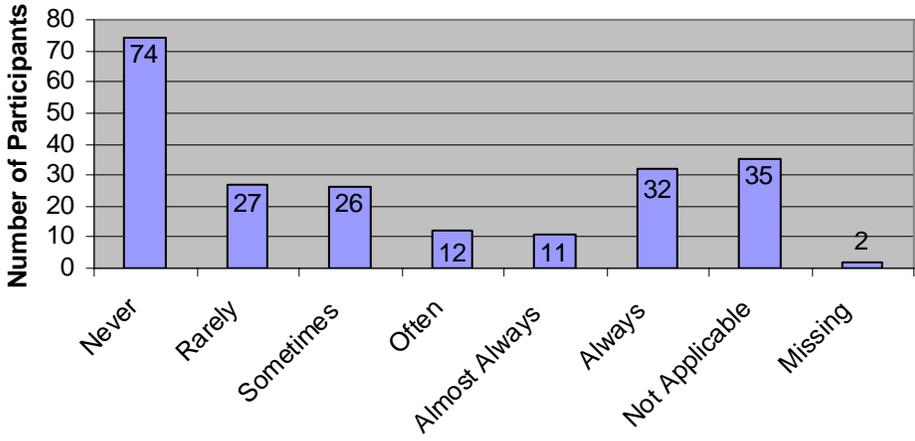
6: Mental health services helped me get housing that I can afford.



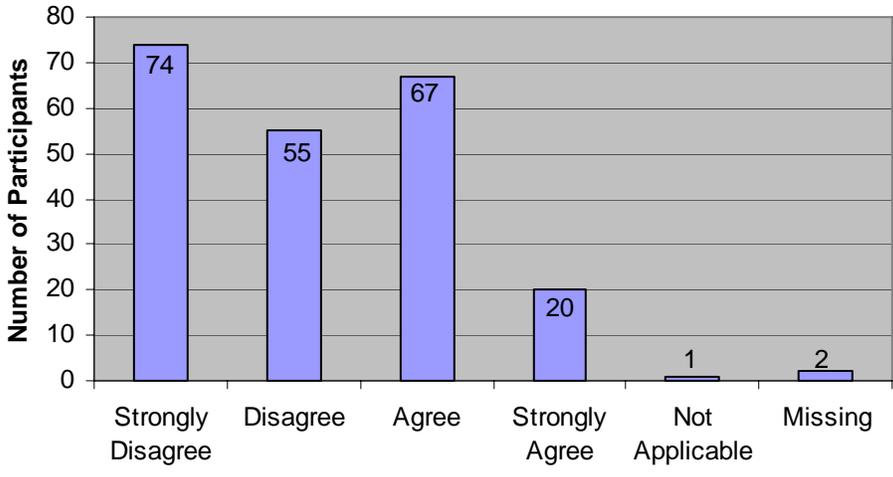
7: I have reliable transportation to get where I need to go.



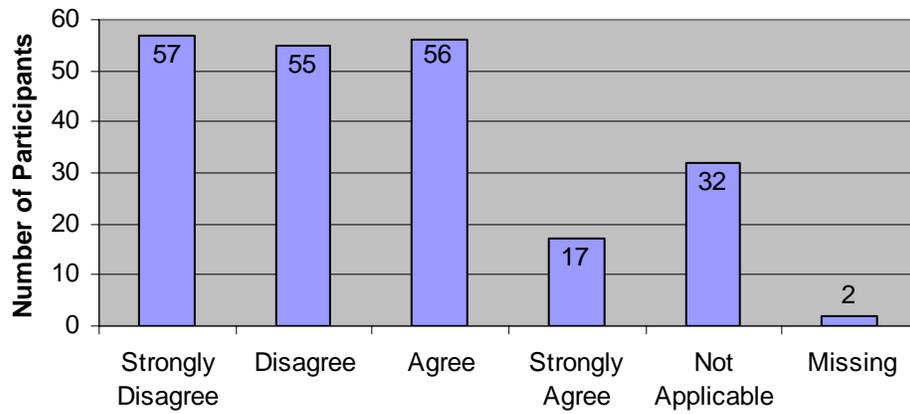
8: Mental health services helped me get reliable transportation.



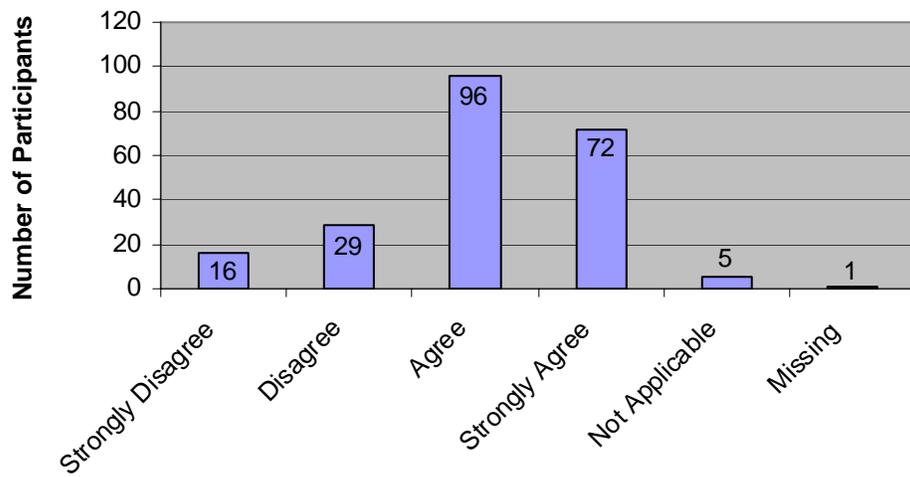
9: I have enough income to live on.

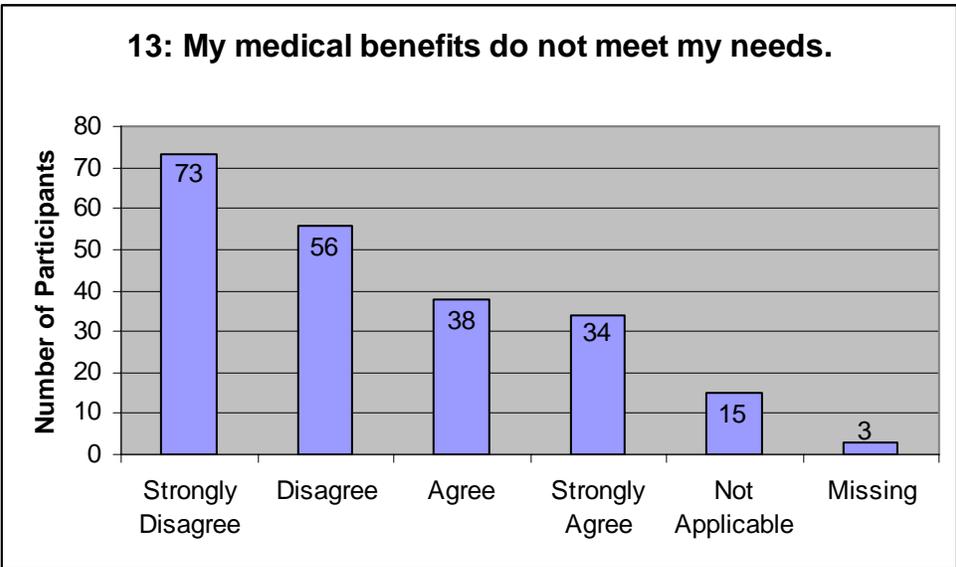
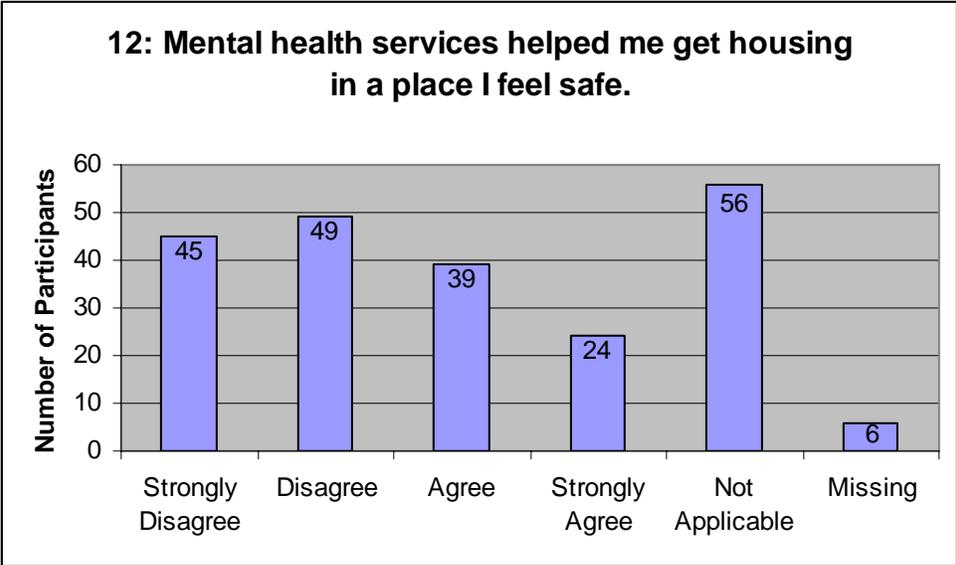


10: Mental health services helped me obtain enough income to live on.

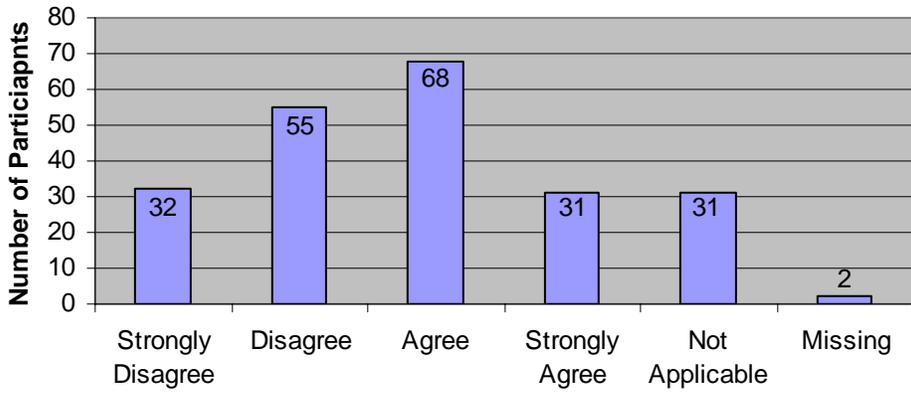


11: I live in a safe location.

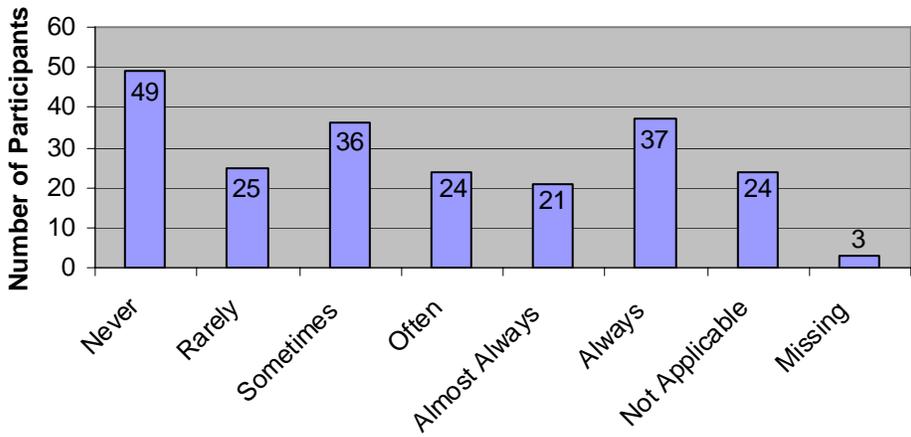




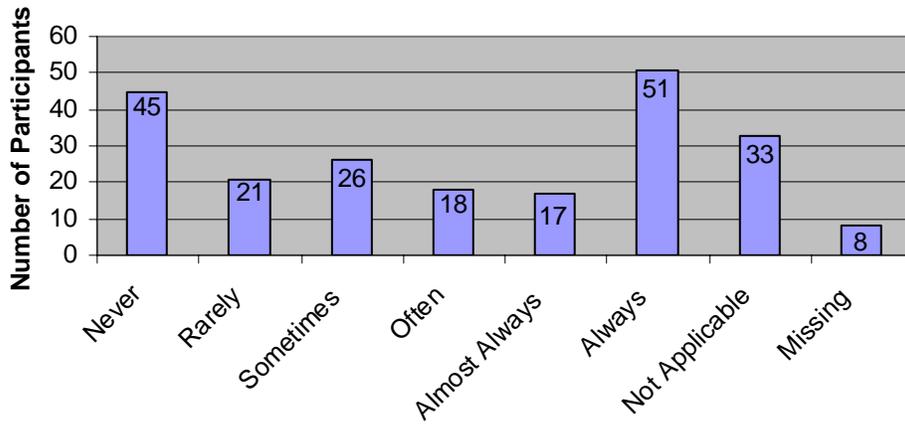
14: Mental health services helped me get medical benefits that meet my needs.



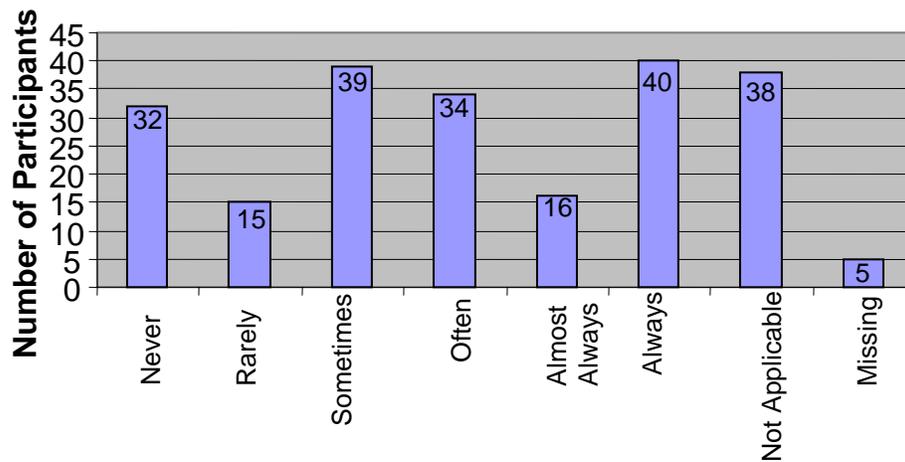
15: There was a consumer peer advocate to turn to when I needed one.



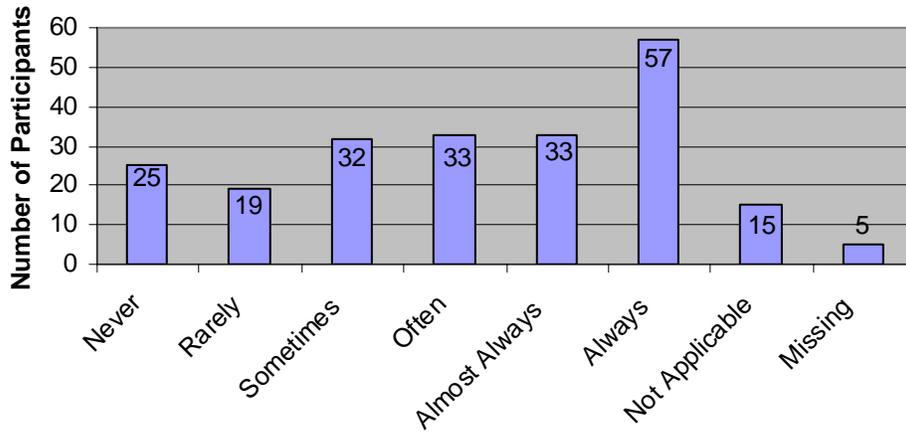
16: There are consumers working as paid employees in the mental health agency where I receive services.



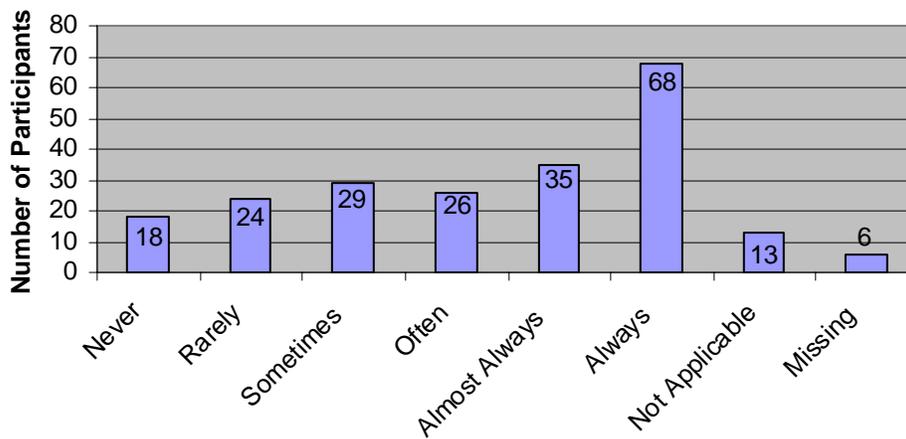
17: I found helpful services in consumer run programs that were not available in other mental health services.



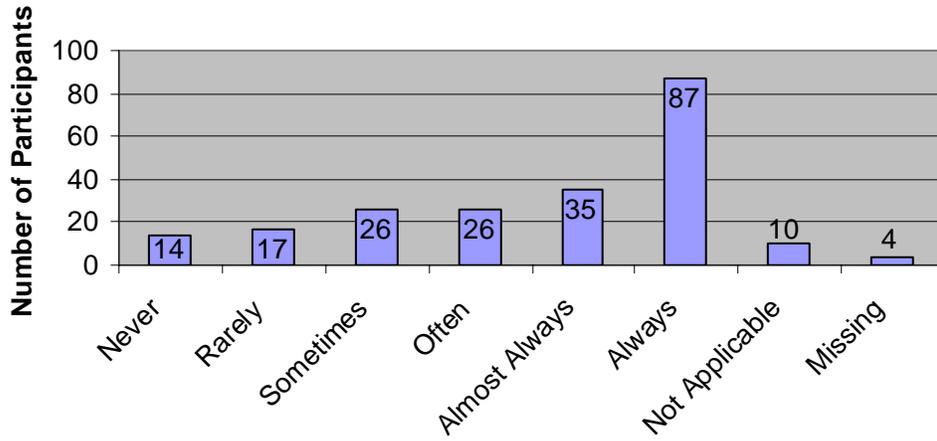
18: Staff supports my right to try new things, take a risk or make a mistake.



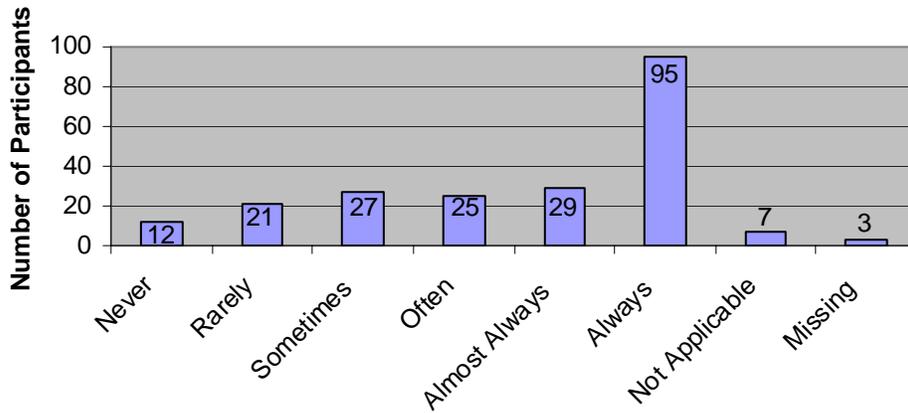
19: I have a say in what happens to me when I am in crisis.



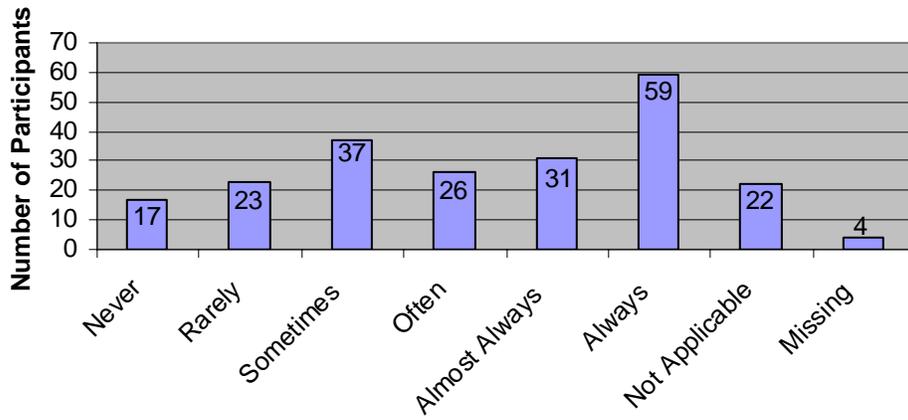
20: Staff give me complete information in words I understand before I consent to treatment or medication.



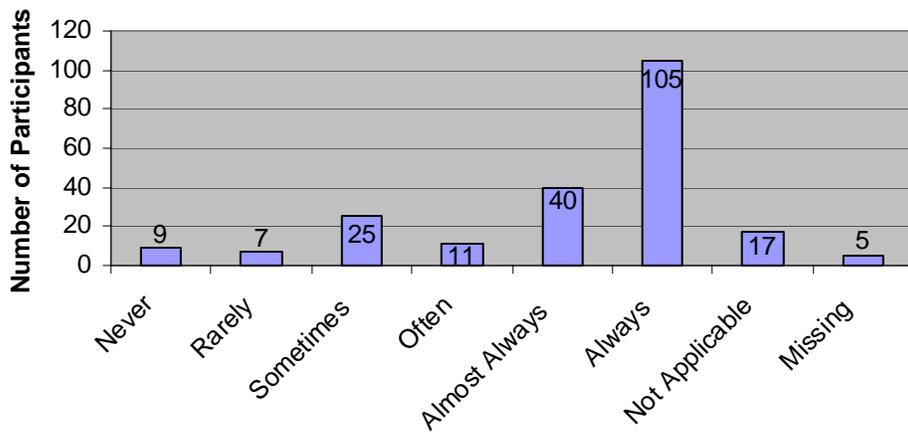
21: Staff encourage me to do things that are meaningful to me.



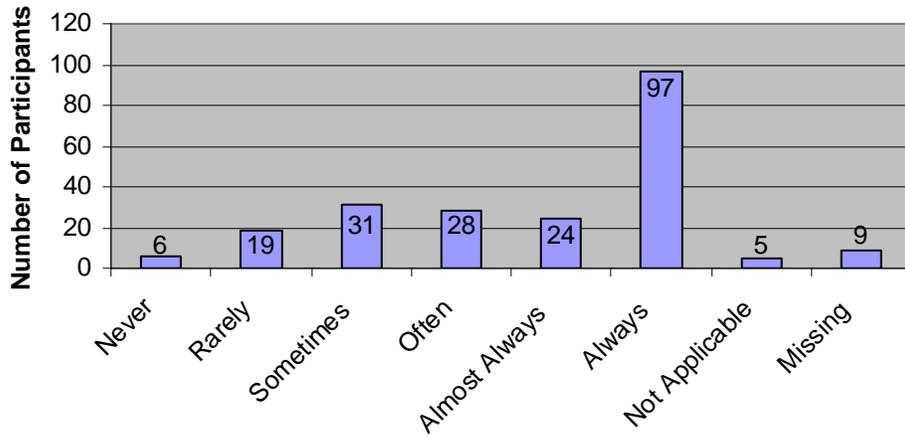
22: Staff stood up for me to get the services and resources I needed.



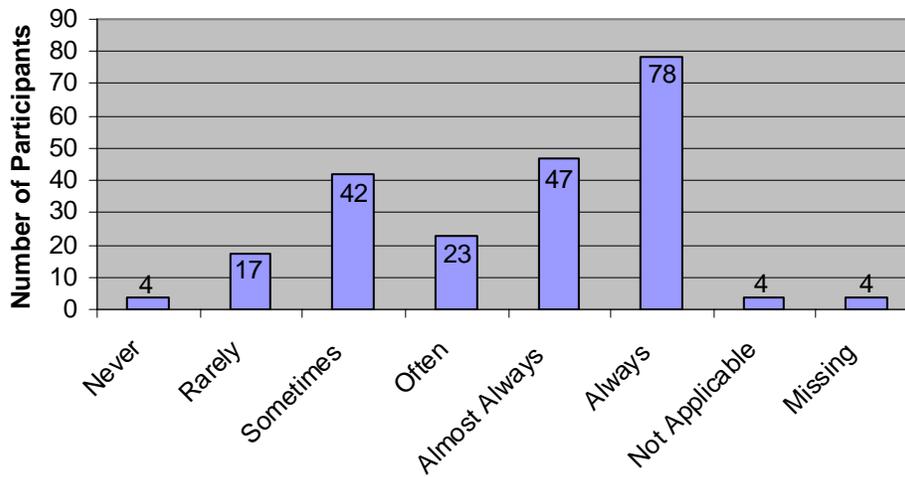
23: Staff treat me with respect regarding my cultural background.



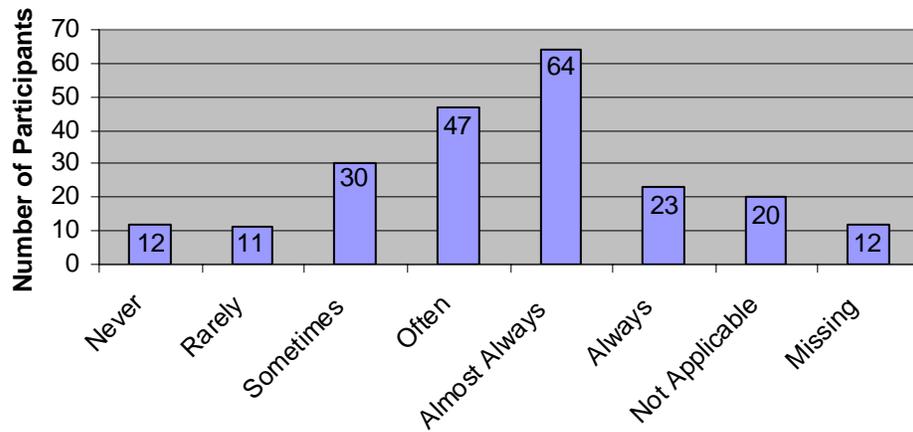
24: Staff believe that I can grow, change and recover.



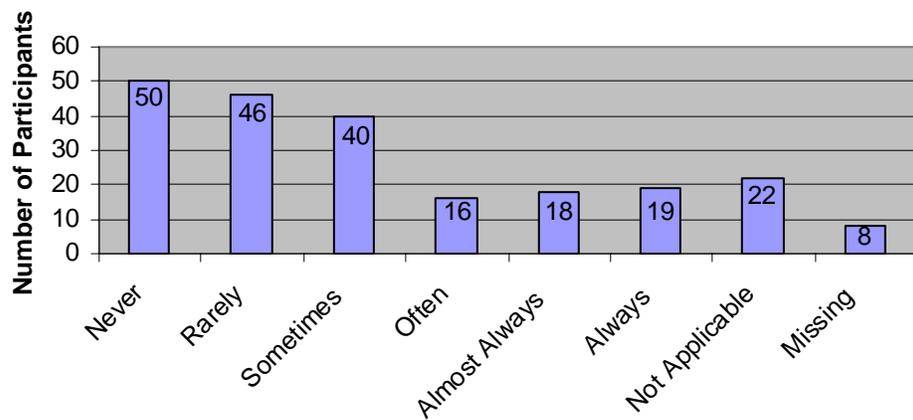
25: Staff listen carefully to what I say.



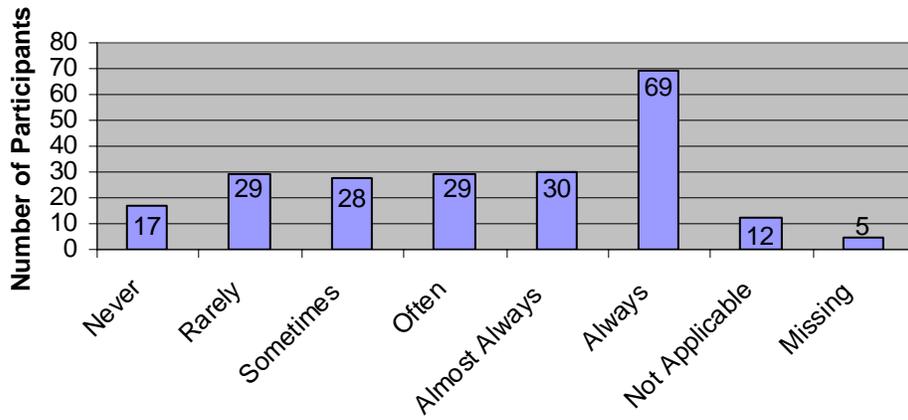
26: Staff lack up-to-date knowledge on the most effective treatments.



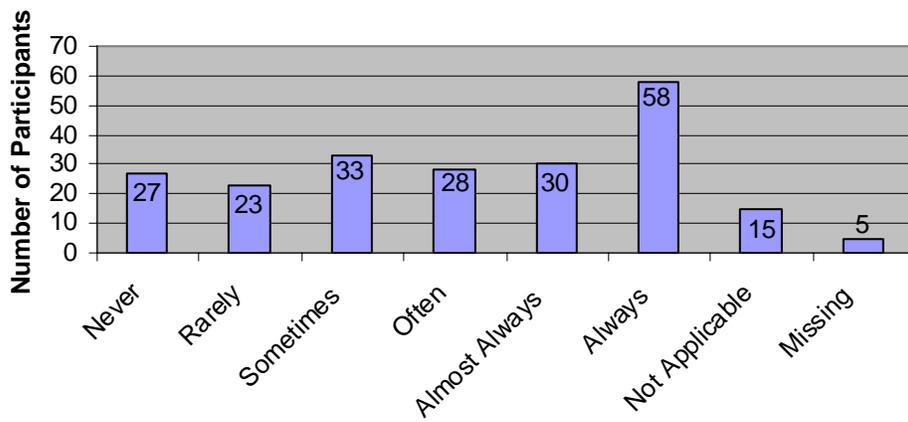
27: I can have a say in how my service agency operates.



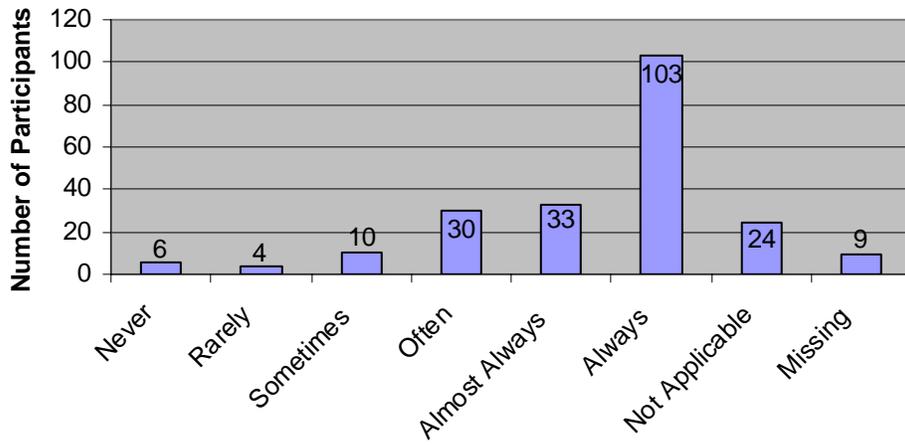
28: Staff see me as an equal partner in my treatment program.



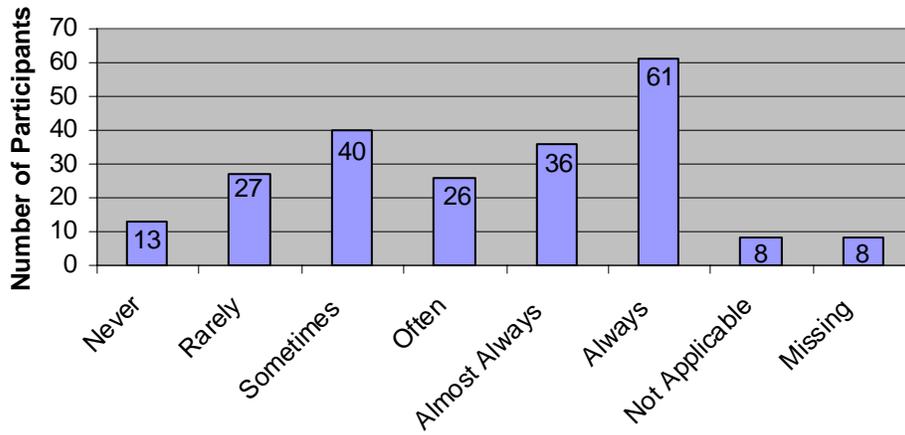
29: My treatment goals are stated in my own words.



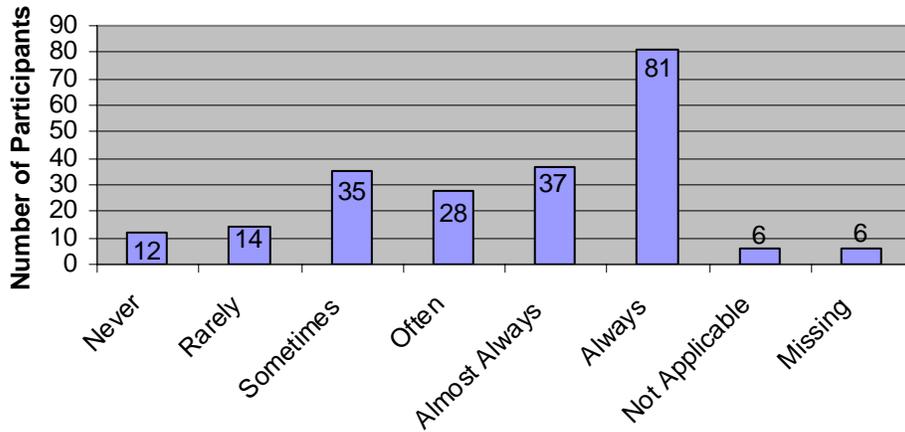
30: Mental health staff interfere with my personal relationships.



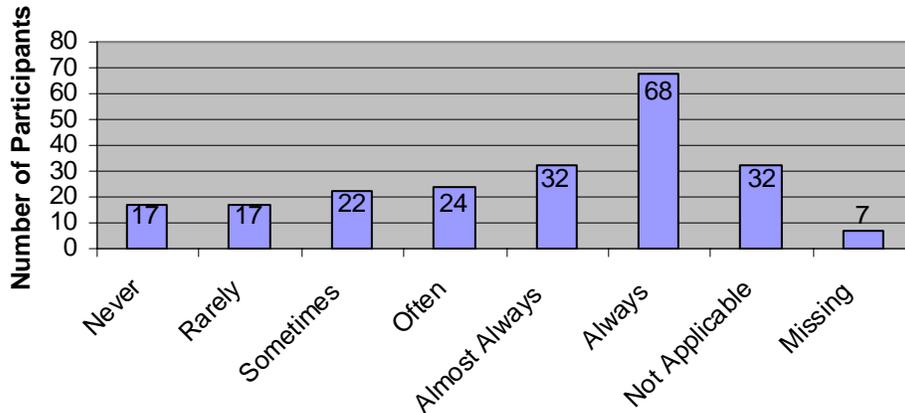
31: Mental health staff help me build on my strengths.



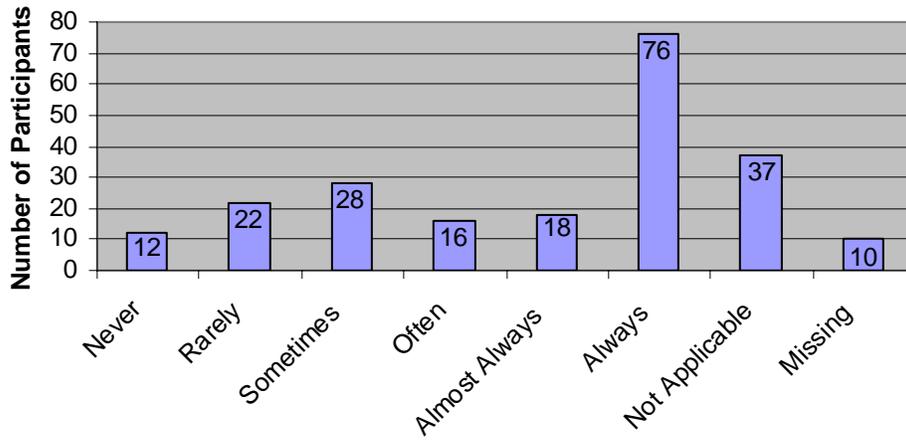
32: Mental health staff support my self-care or wellness.



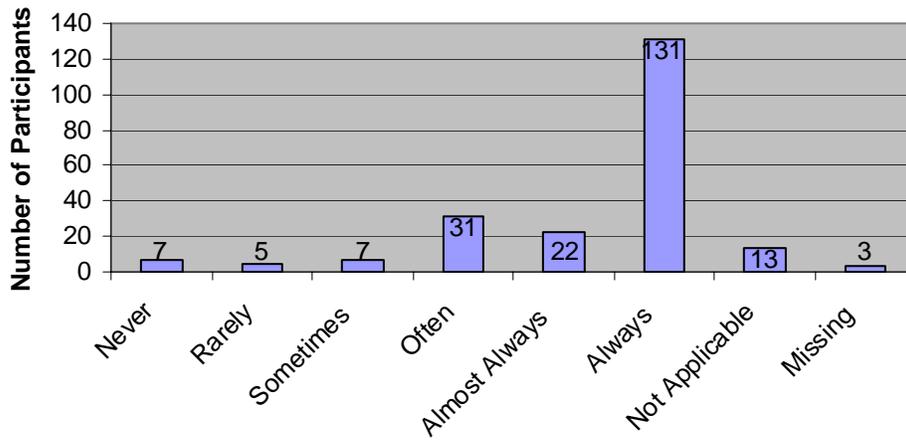
33: Staff help me stay out of psychiatric hospitals and avoid involuntary treatment.



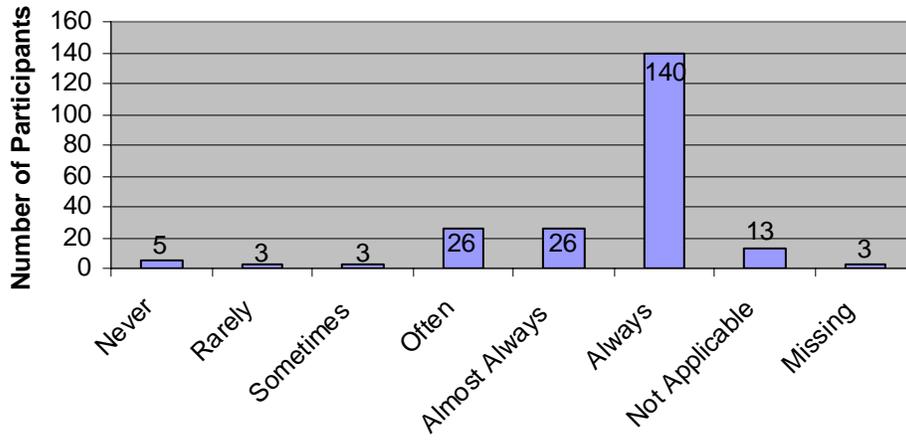
34: My right to refuse treatment is respected.



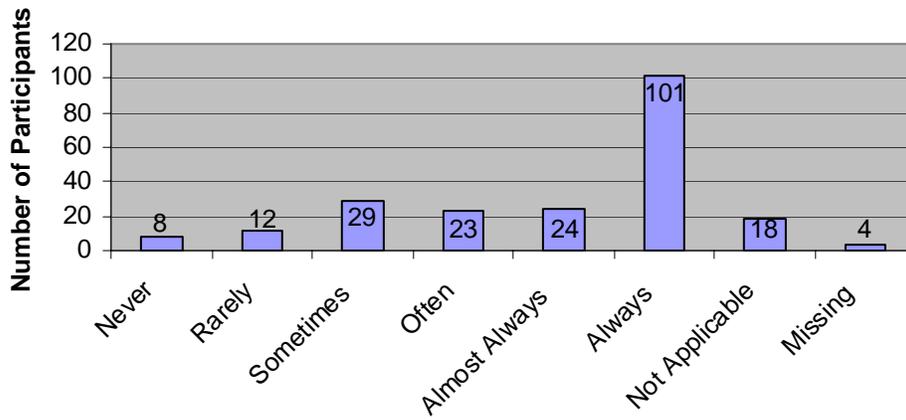
35: Treatment or medication was forced on me.



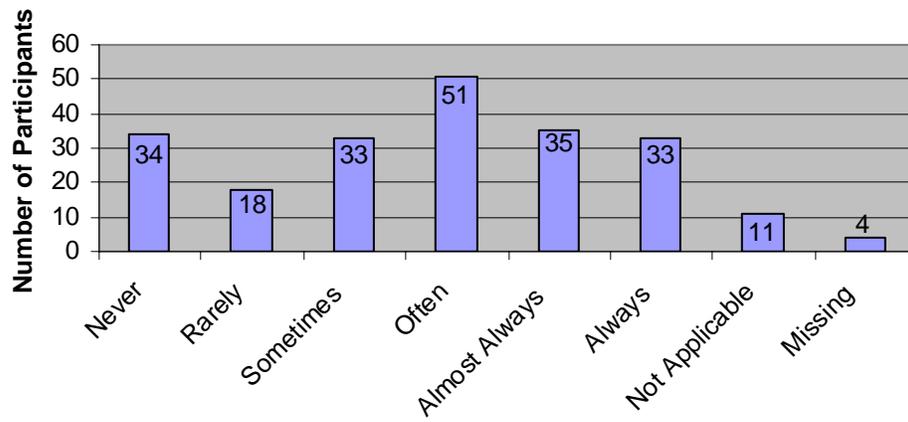
36: Staff use pressure, threats or force in my treatment.



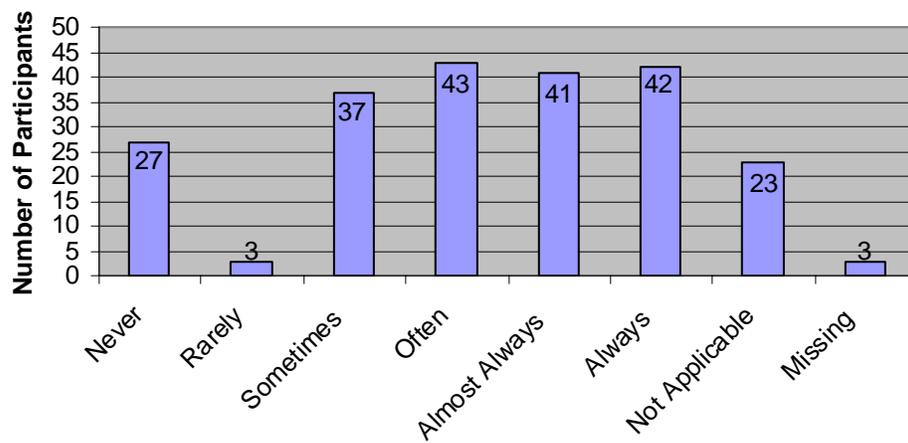
37: Staff respect my wishes about who is and who is not given information about my treatment.



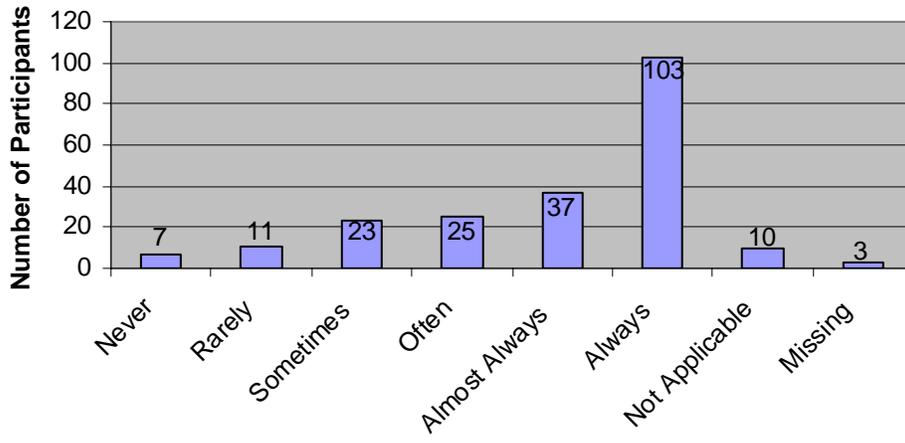
38: The time I have with my psychiatrist is too brief to be helpful.



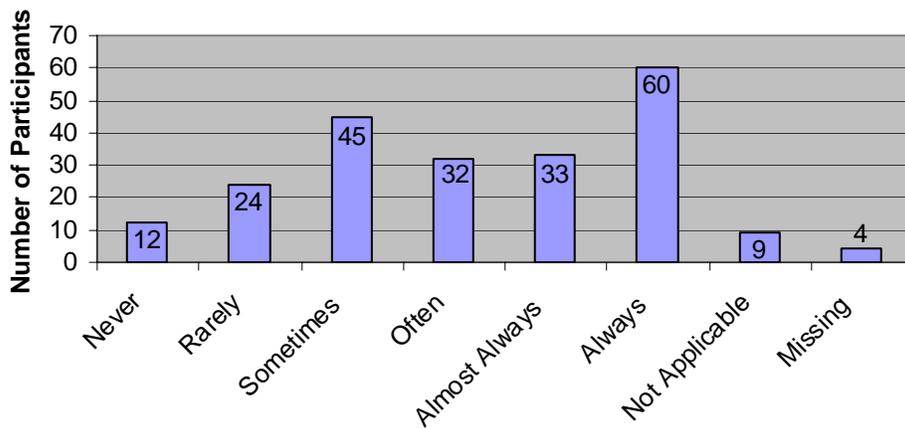
39: There are too many changes in the staff who provide my services.



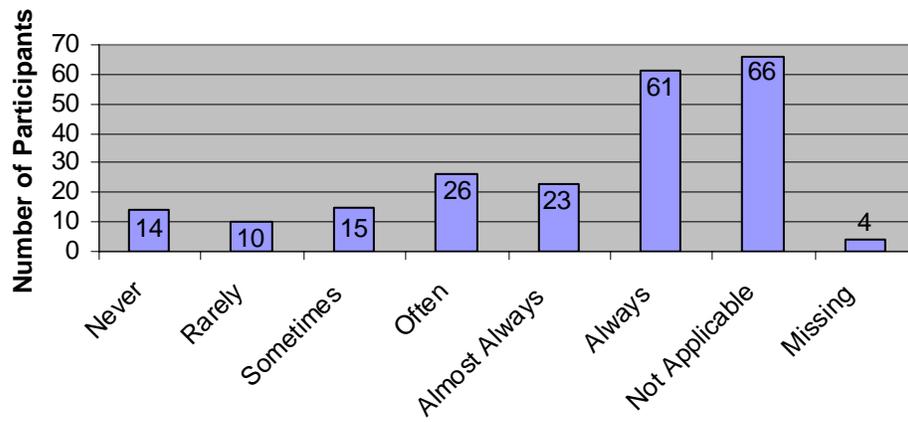
40: The doctor worked with me to get on medications that were most helpful for me.



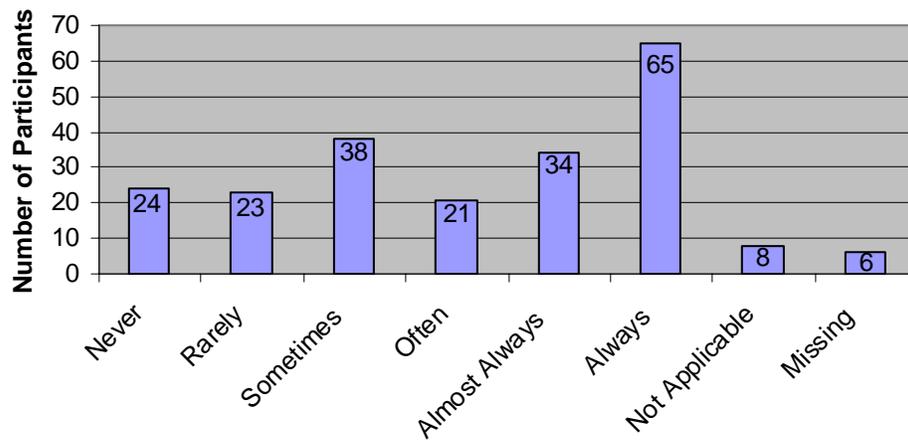
41: I have information or guidance to get the services and supports I need, both inside and outside my mental health agency.



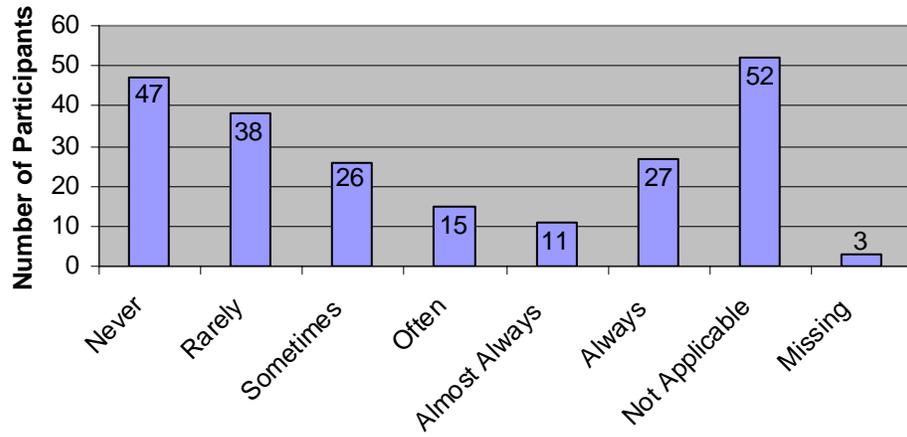
42: I can get combined services and supports for both substance abuse and mental illness.



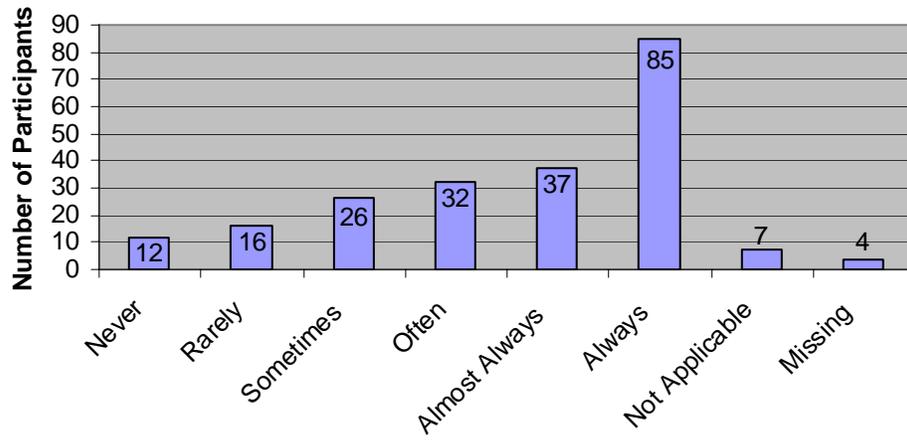
43: I can see a therapist when I need to.



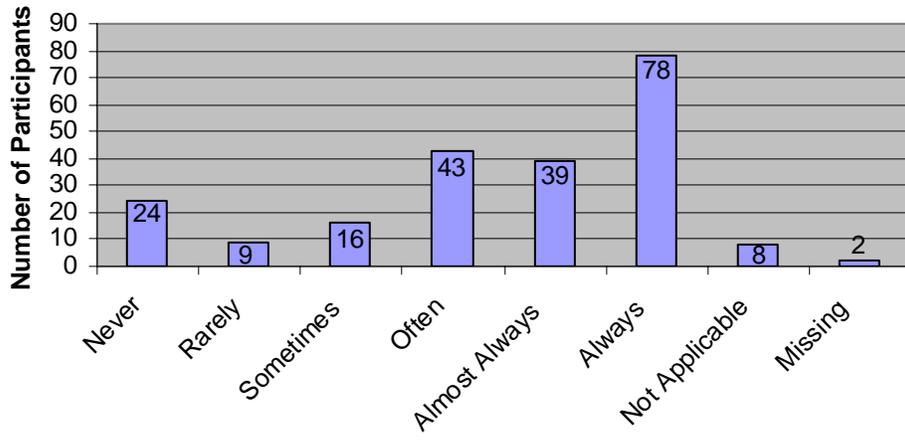
44: My family gets the education or supports they need to be helpful to me.



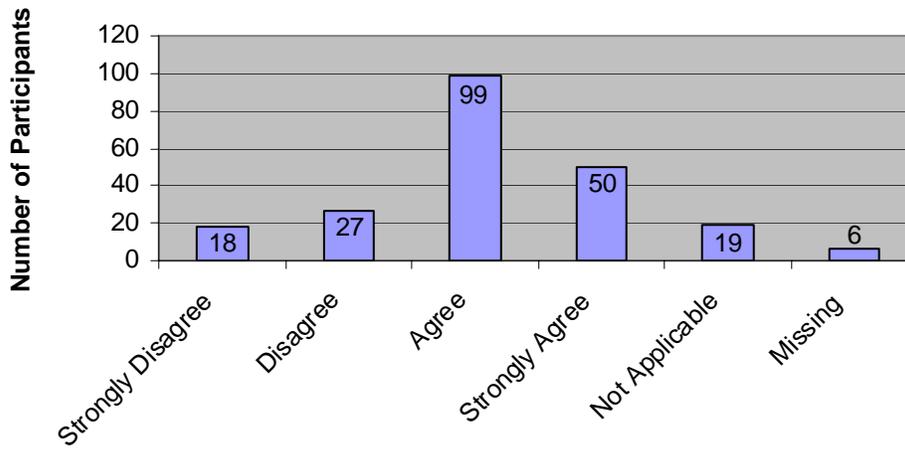
45: I am given information about medication side effects in words I understand.



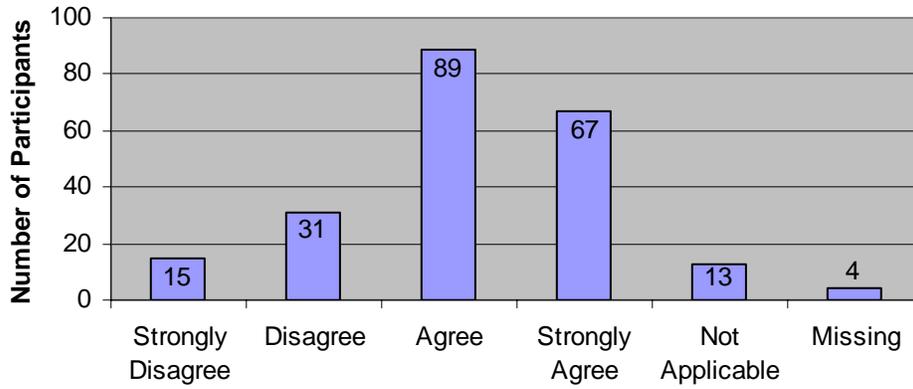
46: I am treated as a psychiatric label rather than as a person.



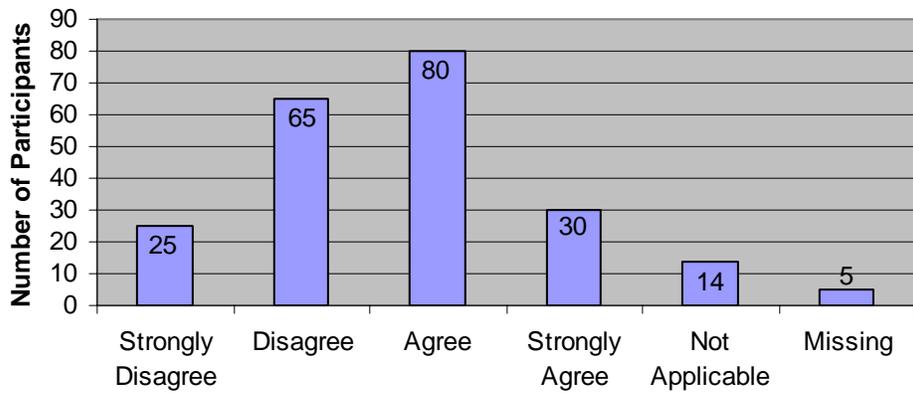
47: I have access to other consumers who act as role models.



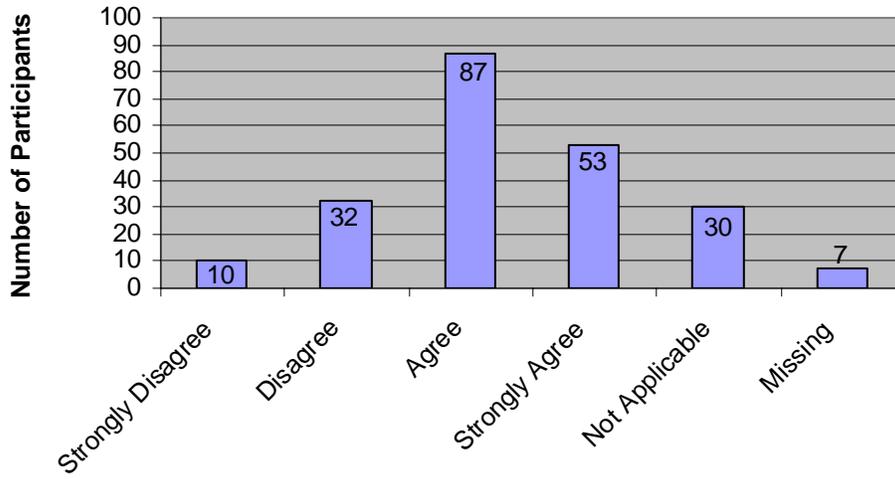
48: I am encouraged to use consumer-run programs.



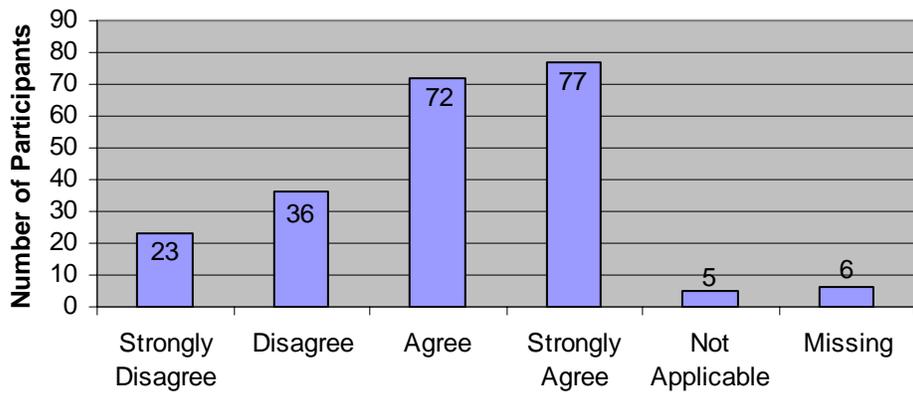
49: I do not have enough good service options to choose from.



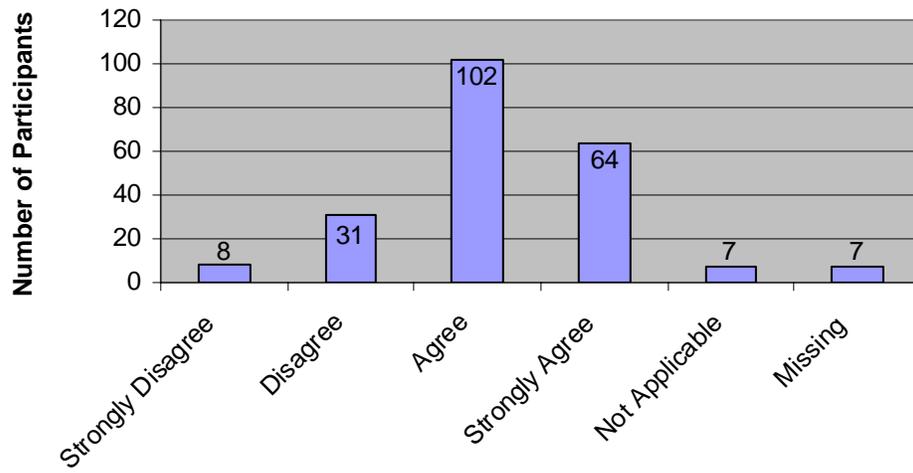
50: Service programs restrict my freedom to associate with people of my choice.



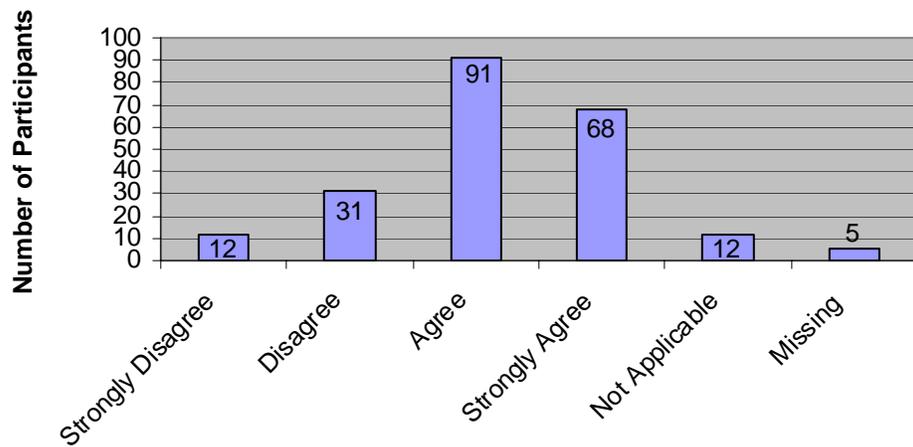
51: I have a place to live that feels like a comfortable home to me.



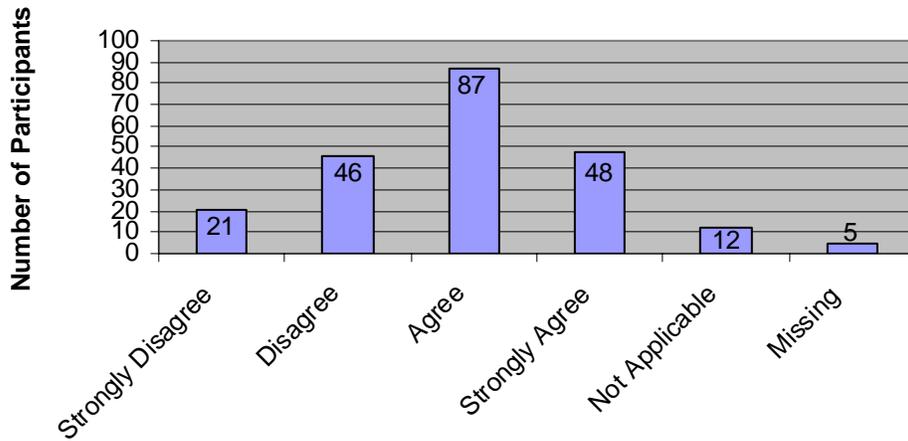
52: Staff respect me as a whole person.



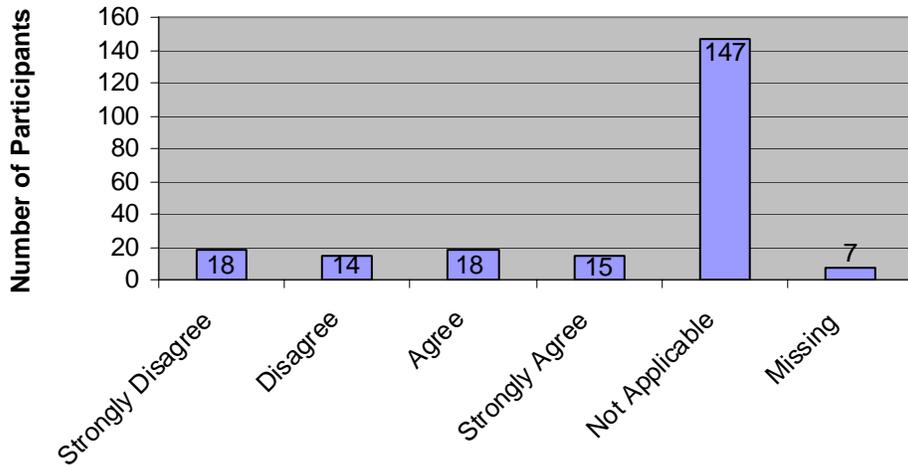
53: Staff treat me as though I will never be able to function well.



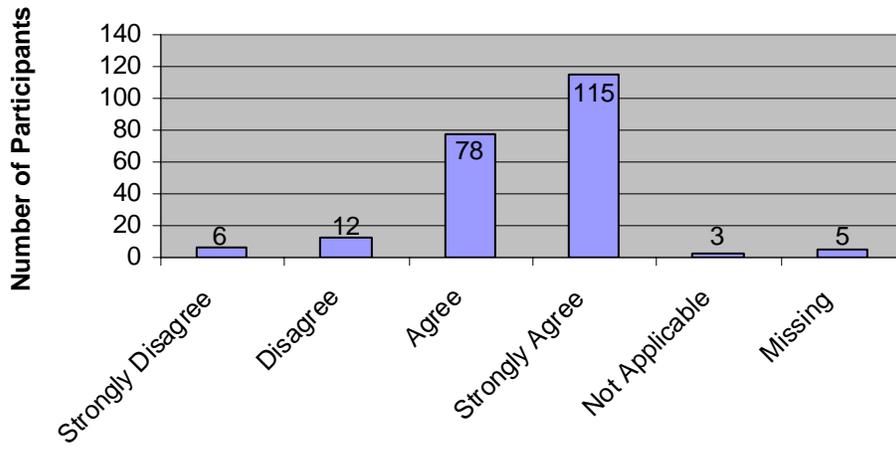
54: Staff do not understand my experience as a person with mental health problems.



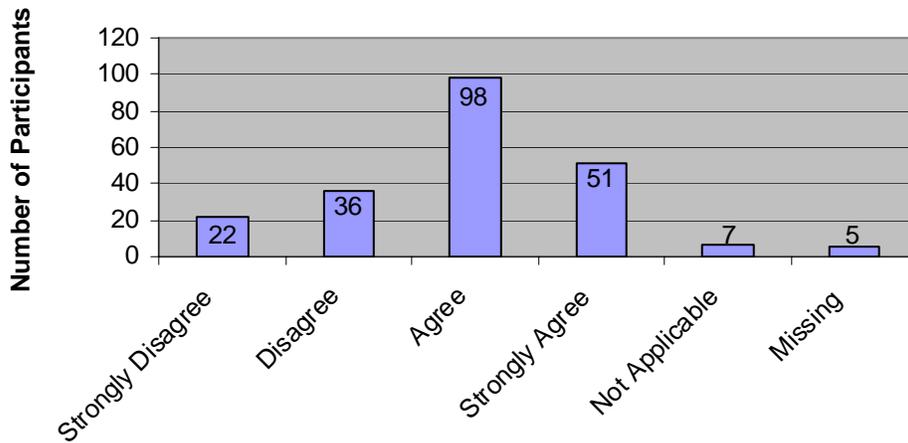
55: I receive support to parent my children.

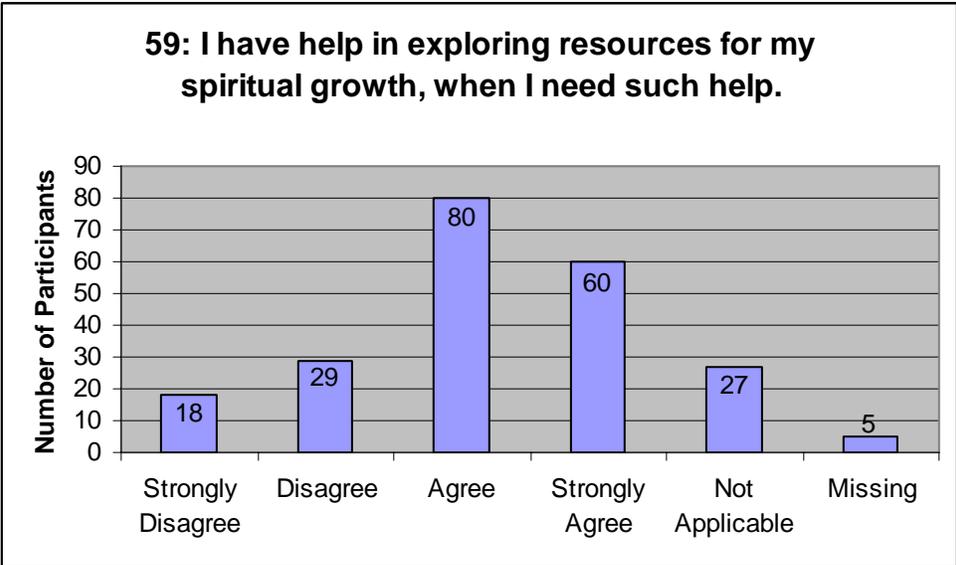
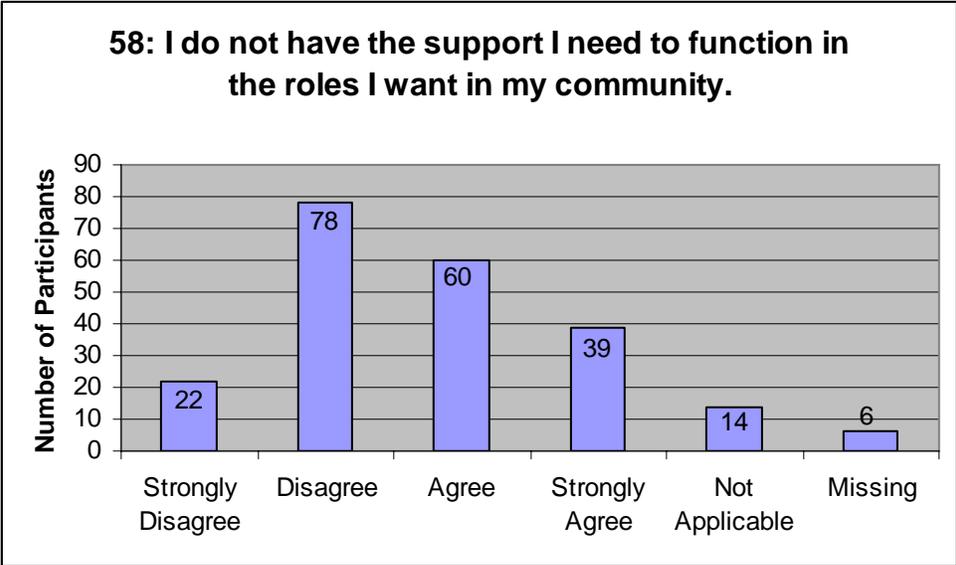


56: There is at least one person who believes in me.

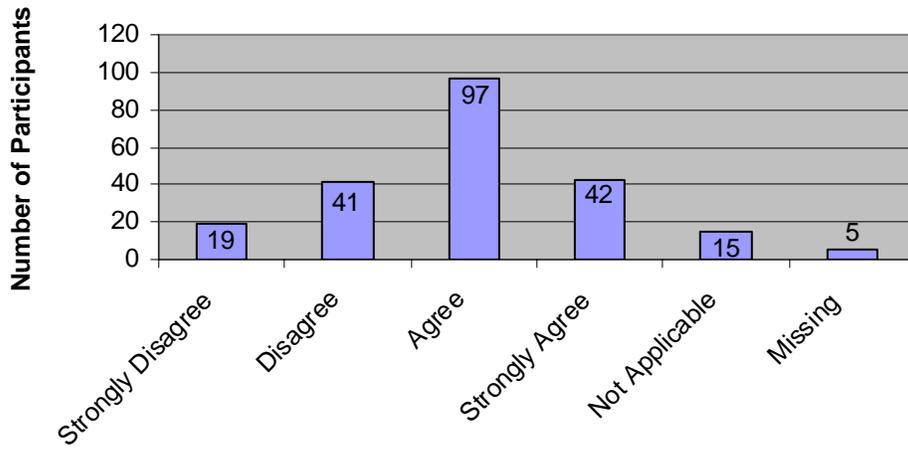


57: I have supports to develop friendships with people outside the mental health system.

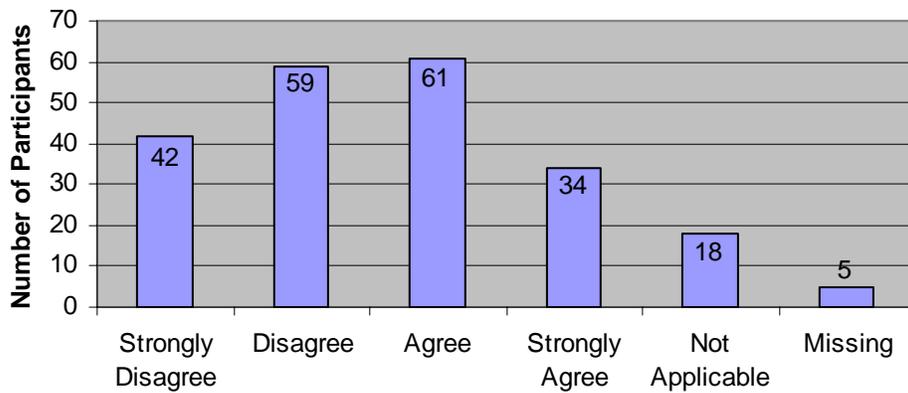




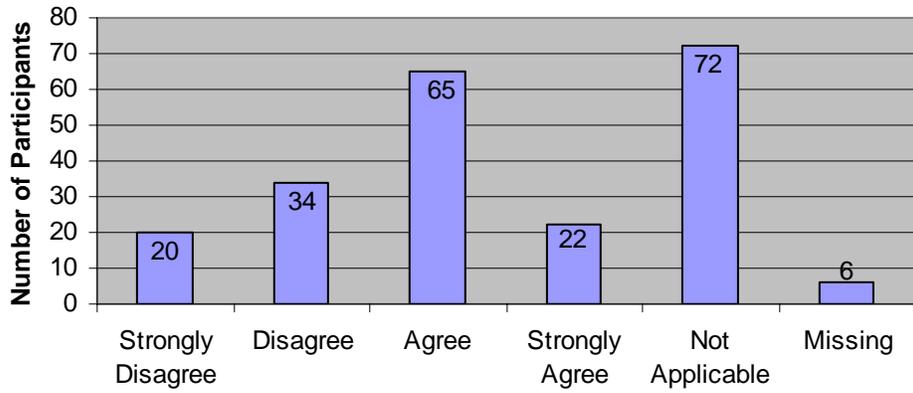
60: The mental health staff ignore my physical health.



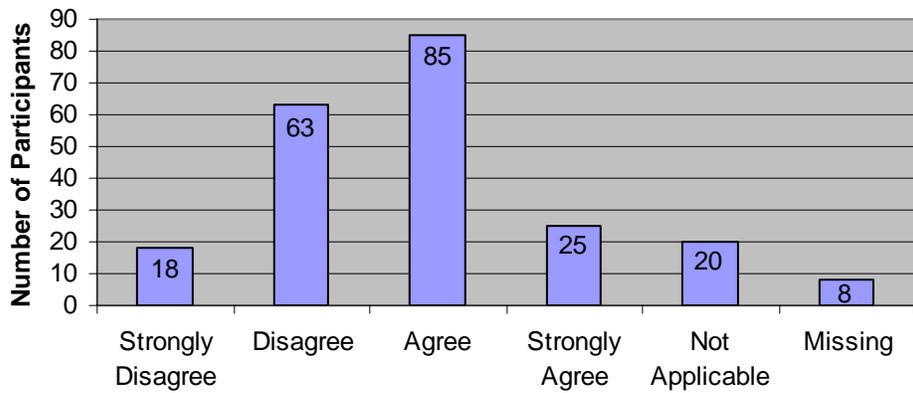
61: I am afraid that if I do too well I will lose my supports and services.



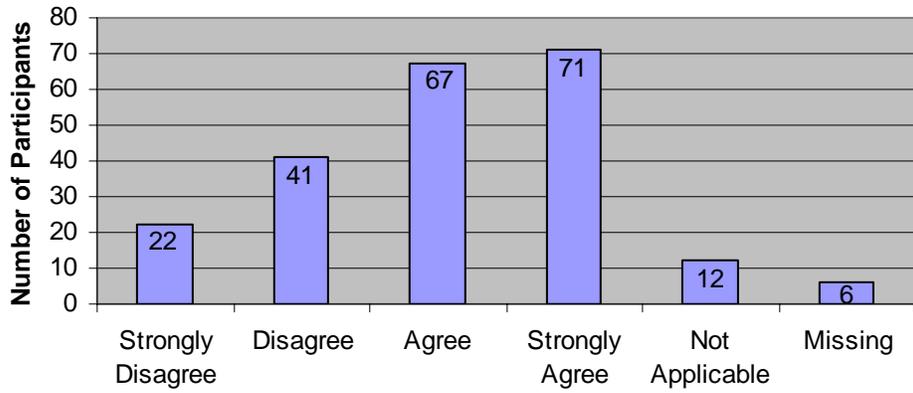
62: Complaints or grievances about mental health services were respectfully resolved.



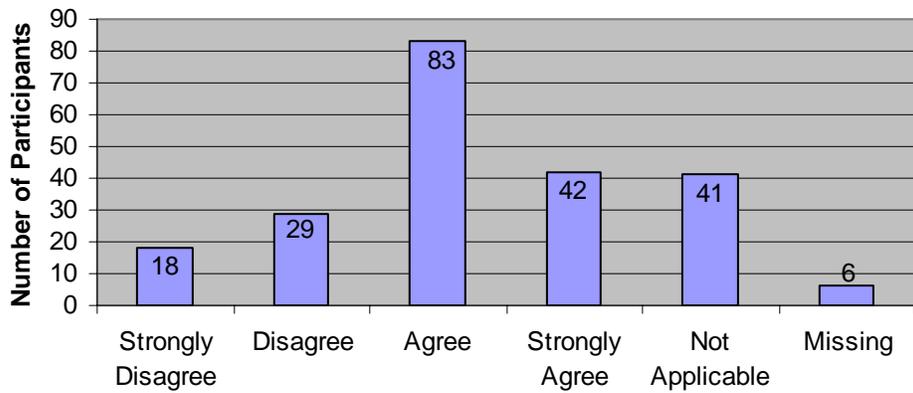
63: Services are not flexible to meet my changing needs.



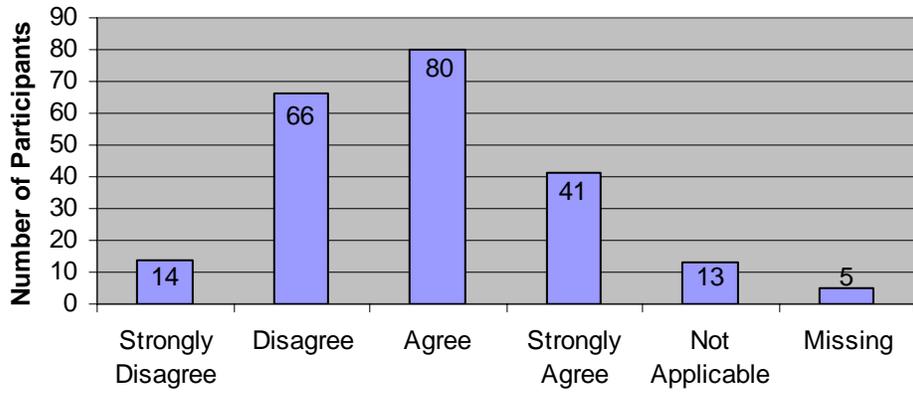
64: Mental health services have caused me emotional or physical harm.



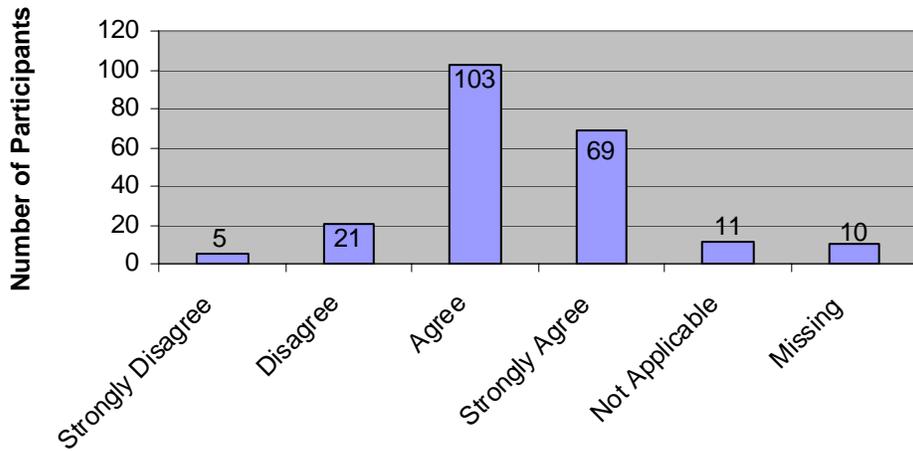
65: I have access to services for trauma or abuse as needed.



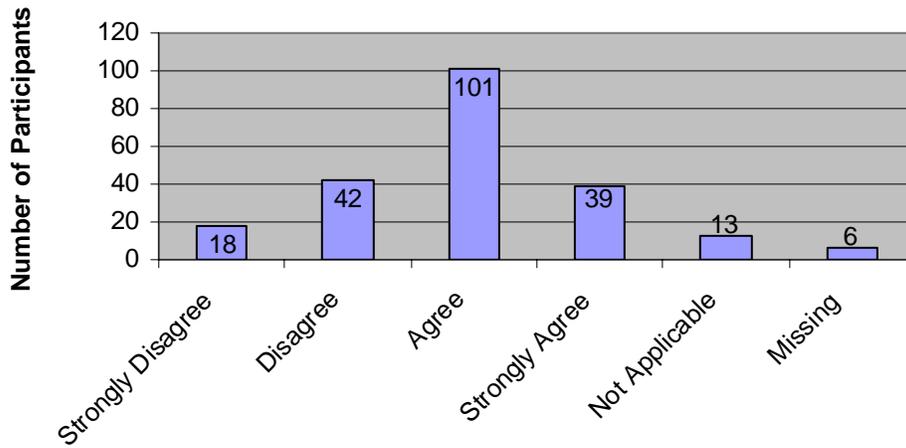
66: I cannot get the services I need when I need them.



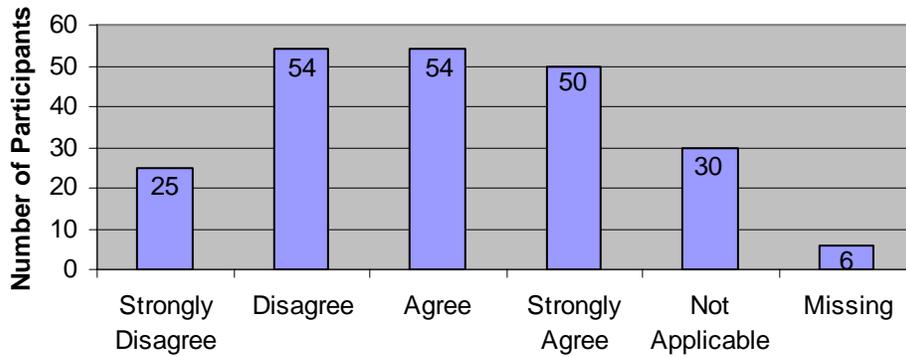
67: Staff encourage me to take responsibility for how I live my life.



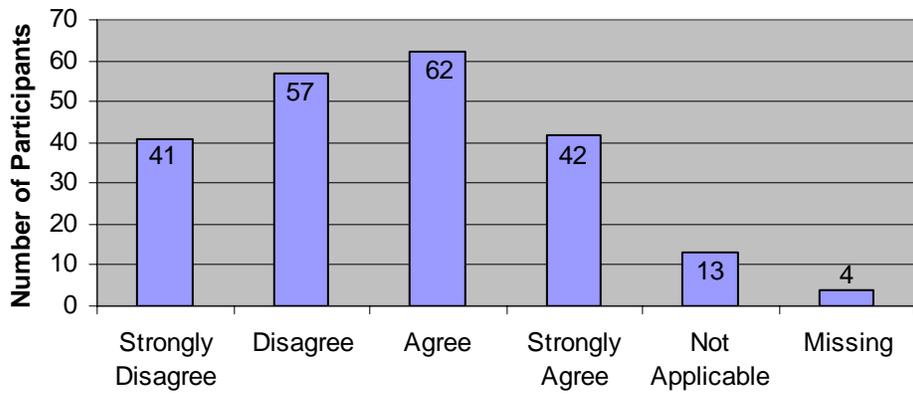
68: Services help me develop the skills I need.



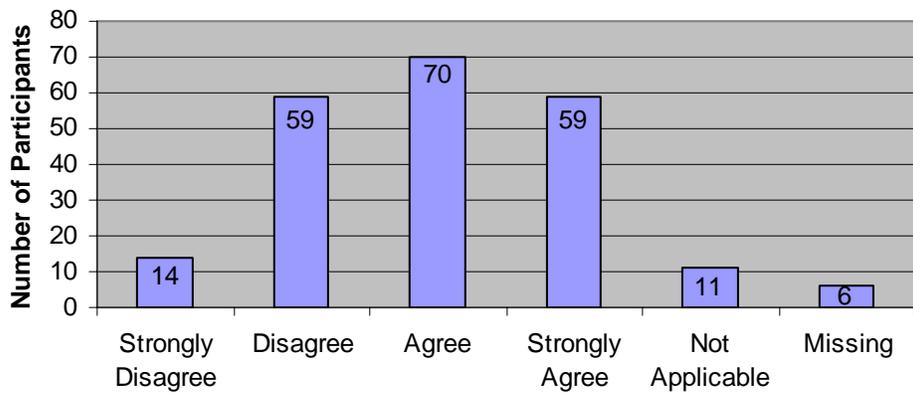
69: I have help in creating a plan for how I want to be treated in the event of a crisis, such as an advance directive.



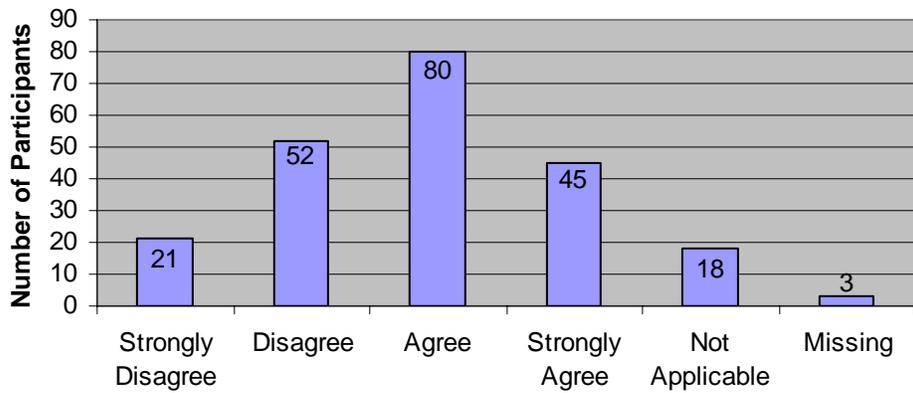
70: Mental health services led me to be more dependent, not more independent.



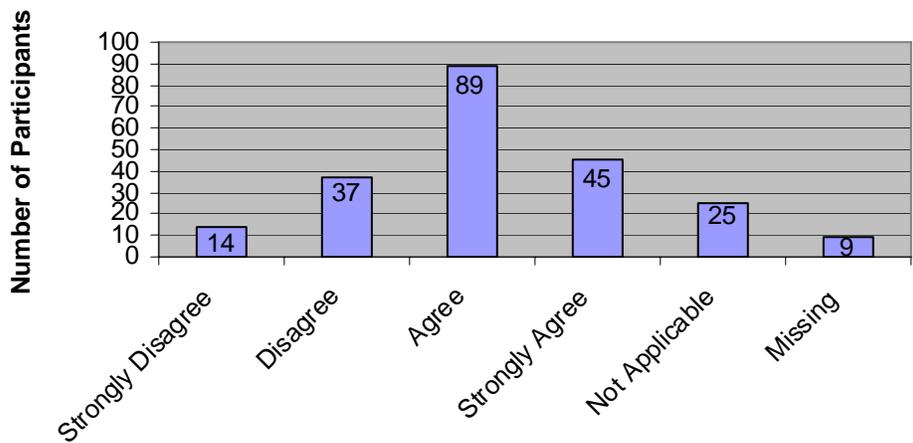
71: Mental health services fed into my negative feelings about myself.



72: I lack the information or resources I need to uphold my client rights and basic human rights.



73: I have support for challenging negative stereotypes, stigma and/or discrimination.



Appendix E:
73 Items Ranked By Mean Importance Rating
(With Minimum Rating of 1 and Maximum of 10)

Appendix E: 73 Items Ranked By Mean Importance Rating (With Minimum Rating of 1 and Maximum of 10)

Item number and statement	N	Mean	Standard Deviation
Q40: The doctor worked with me to get on medications that were most helpful for me.	211	9.14	1.814
Q52: Staff respect me as a whole person.	209	8.92	2.111
Q25: Staff listen carefully to what I say.	212	8.82	2.165
Q56: There is at least one person who believes in me.	211	8.82	2.282
Q51: I have a place to live that feels like a comfortable home to me.	209	8.81	2.341
Q22: Staff stood up for me to get the services and resources I needed.	211	8.66	2.374
Q37: Staff respect my wishes about who is and who is not given information about my treatment.	209	8.64	2.384
Q20: Staff give me complete information in words I understand before I consent to treatment or medication.	212	8.64	2.297
Q19: I have a say in what happens to me when I am in crisis.	209	8.62	2.369
Q28: Staff see me as an equal partner in my treatment program.	209	8.60	2.349
Q14: Mental health services helped me get medical benefits that meet my needs.	211	8.58	2.548
Q45: I am given information about medication side effects in words I understand.	208	8.57	2.386
Q41: I have information or guidance to get the services and supports I need, both inside and outside my mental health agency.	209	8.56	2.289
Q24: Staff believe that I can grow, change and recover.	211	8.55	2.345
Q43: I can see a therapist when I need to.	210	8.53	2.458
Q67: Staff encourage me to take responsibility for how I live my life.	209	8.48	2.268
Q21: Staff encourage me to do things that are meaningful to me.	212	8.46	2.468
Q5: I have housing that I can afford.	214	8.44	2.748

Item number and statement	N	Mean	Standard Deviation
Q33: Staff help me say out of psychiatric hospitals and avoid voluntary treatment.	203	8.43	2.589
Q70: Mental health services led me to be more dependent, not independent.	212	8.42	2.535
Q11: I live in a safe location.	215	8.41	2.547
Q13: My medical benefits do not meet my needs (for example, no dental care, no eye care, no choice in doctors, limited prescriptions, etc.).	214	8.40	2.655
Q23: Staff treat me with respect regarding my cultural background (think of race, ethnicity, religion, language, age, sexual orientation, etc.).	208	8.38	2.588
Q9: I have enough income to live on.	215	8.37	2.853
Q34: My right to refuse treatment is respected.	198	8.33	2.579
Q31: Mental health staff help me build on my strengths.	207	8.33	2.409
Q65: I have access to services for trauma or abuse as needed.	204	8.28	2.550
Q32: Mental health staff support my self-care or wellness.	207	8.28	2.527
Q46: I am treated as a psychiatric label rather than as a person.	209	8.27	2.853
Q38: The time I have with my psychiatrist is too brief to be helpful.	212	8.26	2.669
Q7: I have reliable transportation to get where I need to go.	214	8.23	2.759
Q69: I have help in creating a plan for how I want to be treated in the event of a crisis, such as an advance directive.	206	8.20	2.55
Q66: I cannot get the services I need when I need them.	209	8.15	2.720
Q57: I have supports to develop friendships with people outside the mental health system.	210	8.15	2.553
Q62: Complaints or grievances about mental health services were respectfully resolved.	195	8.12	2.653
Q73: I have support for challenging negative stereotypes, stigma and/or discrimination.	207	8.1	2.777
Q54: Staff do not understand my experience as a person with mental health problems.	207	8.07	2.648

Item number and statement	N	Mean	Standard Deviation
Q72: I lack the information or resources I need to uphold my client rights and basic human rights.	208	8.07	2.798
Q29: My treatment plan goals are stated in my own words.	210	8.06	2.596
Q48: I am encouraged to use consumer-run programs (for example, support groups, drop-in centers, etc.).	210	8.04	2.583
Q68: Services help me develop the skills I need.	208	8.00	2.657
Q71: Mental health services fed into my negative feelings about myself.	207	7.97	2.795
Q64: Mental health services have caused me emotional or physical harm.	208	7.97	2.866
Q53: Staff treat me as though I will never be able to function well.	206	7.93	2.993
Q35: Treatment or medication was forced upon me.	210	7.91	3.160
Q60: The mental health staff ignore my physical health.	209	7.90	2.714
Q59: I have help in exploring resources for my spiritual growth, when I want such help.	206	7.90	2.807
Q18: Staff supports my right to try new things, take a risk or make a mistake.	212	7.87	2.690
Q61: I am afraid that if I do too well I will lose my supports and services.	209	7.86	2.943
Q36: The time I have with my psychiatrist is too brief to be helpful.	207	7.85	3.197
Q15: There was a consumer peer advocate to turn to when I needed one.	210	7.75	3.004
Q10: Mental health services helped me obtain enough income to live on.	211	7.73	3.177
Q42: I can get combined services and supports for both substance abuse and mental illness.	198	7.71	3.067
Q26: Staff lack up-to-date knowledge on the most effective treatments.	205	7.68	2.880
Q6: Mental health services helped me get housing that I can afford.	208	7.64	3.188
Q58: I do not have the support I need to function in the roles I want in my community.	207	7.63	2.787
Q39: There are too many changes in the staff who provide my services.	210	7.62	2.906
Q63: Services are not flexible to meet my changing needs.	205	7.59	2.695

Item number and statement	N	Mean	Standard Deviation
Q49: I do not have enough good service options to choose from.	207	7.57	2.751
Q12: Mental health services helped me get housing in a place I feel safe.	210	7.50	3.199
Q44: My family gets the education or supports they need to be helpful to me.	200	7.49	3.224
Q55: I receive support to parent my children.	164	7.48	3.468
Q47: I have access to other consumers who act as role models.	207	7.47	2.952
Q17: I found helpful services in consumer run programs that were not available in other mental health services.	207	7.31	2.963
Q27: I can have a say in how my service agency operates.	210	7.16	3.034
Q3: I have a chance to advance my education if I want to.	214	7.14	3.088
Q50: Service programs restrict my freedom to associate with people of my choice.	202	7.02	3.165
Q30: Mental health staff interfere with my personal relationships.	202	7.02	3.259
Q8: Mental health services helped me get reliable transportation.	209	7.01	3.414
Q16: There are consumers working as paid employees in the mental health agency where I receive services.	206	6.96	3.194
Q4: Mental health services helped me in advancing my education if I wanted to.	211	6.95	3.113
Q1: I have paid work opportunities that are meaningful to me.	215	6.95	3.370
Q2: Mental health services helped me get or keep employment.	214	6.94	3.127
Valid N (listwise)	126		

Appendix F:
Phase II Self-Report Prototype
Test Item Reduction Results

Appendix F: Phase II Self-Report Prototype Test Item Reduction Results

What follows is the original 73 self-report items organized under the themes (and sub-themes) which emerged from Phase One findings. Those items marked with an asterisk (*) are incorporated in the 42 item survey. Those items marked with a double asterisk (**) are included in the 10 item subset.

Recovery Theme: Meaningful Activities (involves the findings that work, education, voluntary and/or group advocacy activities that are meaningful to the individual facilitate recovery).

1. I have paid work opportunities that are meaningful to me.
- *2. Mental health services helped me in get or keep employment.
- *3. I have a chance to advance my education if I want to.
4. Mental health services helped me in advancing my education if I wanted to.
- *21. Staff encourage me to do things that are meaningful to me.

Recovery Theme: Basic Material Resources (involves the findings that recovery from mental illness is incumbent on basic material resource needs being met).

- **5. I have housing that I can afford.
6. Mental health services helped me get housing that I can afford.
- *7. I have reliable transportation to get where I need to go.
8. Mental health services helped me get reliable transportation.
- *9. I have enough income to live on.
10. Mental health services helped me obtain enough income to live on.
11. I live in a safe location.
- *12. Mental health services helped me get housing in a place I feel safe.
13. My medical benefits do not meet my needs (for example, no dental care, no eye care, no choice in doctors, limited prescriptions, etc.).
- *14. Mental health services helped me get medical benefits that meet my needs.
- *22. Staff stood up for me to get the services and resources I needed.
- *51. I have a place to live that feels like a comfortable home to me.

Recovery Theme: Peer Support (involves the findings that peer support and consumer operated services in a myriad of forms facilitate recovery).

- *15. There was a consumer peer advocate to turn to when I needed one.
- *16. There are consumers working as paid employees in the mental health agency where I receive services.
17. I found helpful services in consumer run programs that were not available in other mental health services.
47. I have access to other consumers who act as role models.
- **48. I am encouraged to use consumer-run programs (for example, support groups, drop-in centers, etc.).

Recovery Theme: Choice (involves the findings that having choices, as well as support in the process of making choices, regarding housing, work, social, service, treatment as well as other areas of life facilitate recovery).

- 18. Staff support my right to try new things, take a risk or make a mistake.
- **19. I have a say in what happens to me when I am in crisis.
- *20. Staff give me complete information in words I understand before I consent to treatment or medication.
- *34. My right to refuse treatment is respected.
- *49. I do not have enough good service options to choose from.
- 50. Service programs restrict my freedom to associate with people of my choice.

Recovery Theme: Social Relationships (involves the findings concerning the roles social and personal relationships play in facilitating recovery).

- *30. Mental health staff interfere with my personal relationships.
- 55. I receive support to parent my children.
- **56. There is at least one person who believes in me.
- 57. I have supports to develop friendships with people outside the mental health system.

Social Relationships Sub-Theme: Community Integration/Involvement (involves the finding that community integration facilitates recovery).

- **58. I do not have the support I need to function in the roles I want in my community.

Recovery Theme: Formal Service Staff (involves the findings as to the critical roles formal service staff play in helping or hindering the recovery process).

Formal Service Staff Sub-Theme: Helpful Characteristics (involves the findings that there are certain formal service staff characteristics that are helpful to recovery).

- *23. Staff treat me with respect regarding my cultural background (think of race, ethnicity, religion, language, age, sexual orientation, etc.).
- **24. Staff believe that I can grow, change and recover.
- *25. Staff listen carefully to what I say.
- *26. Staff lack up-to-date knowledge on the most effective treatments.
- **52. Staff respect me as a whole person.

Formal Service Staff Sub-Theme: Partnering/Collaborative Relationships (involves the findings that formal service staff partnering or collaborating with consumers facilitates recovery).

- 27. I can have a say in how my service agency operates.
- **28. Staff see me as an equal partner in my treatment program.

- *29. My treatment plan goals are stated in my own words.

Formal Service Staff Sub-Theme: Hindering Characteristics (involves the findings that certain formal service staff characteristics hinder recovery).

- 53. Staff treat me as though I will never be able to function well.
- *54. Staff do not understand my experience as a person with mental health problems.

Recovery Theme: Formal Services (involves the findings that formal service systems' culture, organization, structure, funding, access, choice, quality, range, continuity and other characteristics can help or hinder the process of recovery).

Formal Services Sub-Theme: Helpful System Culture and Orientation (involves the findings that a formal service system's culture and orientation that is holistic and consumer oriented facilitates recovery).

- *31. Mental health staff help me build on my strengths.
- **32. Mental health staff support my self-care or wellness.
- 33. Staff help me stay out of psychiatric hospitals and avoid involuntary treatment.
- 59. I have help in exploring resources for my spiritual growth, when I want such help.

Formal Services Sub-Theme: Hindering System Culture and Orientation (involves the finding that a formal service system's culture and orientation which defines mental health need too narrowly in nature hinders recovery).

- *60. The mental health staff ignore my physical health.
- 61. I am afraid that if I do too well I will lose my supports and services.

Formal Services Sub-Theme: Coercion (involves the finding that coercion within formal service systems hinders recovery).

- 35. Treatment or medication was forced on me.
- **36. Staff use pressure, threats or force in my treatment.

Formal Services Sub-Theme: Confidentiality (involves the finding that respect for the confidentiality of consumers receiving formal services facilitates recovery).

- 37. Staff respect my wishes about who is and who is not given information about my treatment.

Formal Services Sub-Theme: General Hindering Characteristics (involves the findings that there are characteristics in formal services that hinder recovery).

- 38. The time I have with my psychiatrist is too brief to be helpful.
- 39. There are many changes in the staff who provide my services.

- 62. Complaints or grievances about mental health services were respectfully resolved.
- 63. Services are not flexible to meet my changing needs.
- *64. Mental health services have caused me emotional or physical harm.

Formal Services Sub-Theme: Access to Services (involves the findings as to getting the formal services that consumers feel they need and find helpful facilitates recovery).

- *40. The doctor worked with me to get on medications that were most helpful for me.
- *41. I have information and/or guidance to get the services and supports I need, both inside and outside my mental health agency.
- 42. I can get combined services and supports for both substance abuse and mental illness.
- *43. I can see a therapist when I need to.
- 65. I have access to specialized services for trauma or abuse as needed.
- *66. I cannot get the services I need when I need them.

Formal Services Sub-Theme: Education (involves the findings that there are education roles with respect to formal services that facilitate recovery).

- *44. My family gets the education or supports they need to be helpful to me.
- 45. I am given information about medication side effects in language I understand.

Formal Services Sub-Theme: External Stigma/Prejudice (involves the findings that stigma and prejudice hinder recovery).

- *46. I am treated as a psychiatric label rather than as a person.
- 73. I have support for challenging negative stereotypes, stigma and/or discrimination.

Recovery Theme: Self/Holism (involves the findings that characteristics that relate to one's sense of self, such as self-reliance, as well as having a holistic and human rights focus can facilitate recovery and other such characteristics, such as low self-esteem, can hinder recovery).

- 67. Staff encourage me to take responsibility for how I live my life.
- *68. Services help me develop the skills I need.
- 69. I have assistance in creating a plan for how I want to be treated in the event of a crisis, such as an advance directive.
- *70. Mental health services led me to be more dependent, not independent.
- 71. Mental health services fed into my negative feelings about myself.
- *72. I lack the information or resources I need to uphold my client and basic human rights.

Appendix G:
ROSI Consumer Self-Report Survey

Appendix G: ROSI Consumer Self-Report Survey

Recovery Oriented System Indicators (ROSI) Consumer Survey

Purpose: To provide the best possible mental health services, we want to know what things helped or hindered your progress during the past six (6) months. Please follow the directions and complete all four sections.

Section One Directions: Please read each statement and then circle the response that best represents your situation *during the past six months*. These responses range from “Strongly Disagree” to “Strongly Agree.” If the statement was about something you did not experience, circle the last response “Does Not Apply To Me.”

1. There is at least one person who believes in me.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me
2. I have a place to live that feels like a comfortable home to me.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me
3. I am encouraged to use consumer-run programs (for example, support groups, drop-in centers, etc.).	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me
4. I do not have the support I need to function in the roles I want in my community.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me
5. I do not have enough good service options to choose from.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me
6. Mental health services helped me get housing in a place I feel safe.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me
7. Staff do not understand my experience as a person with mental health problems.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me
8. The mental health staff ignore my physical health.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me
9. Staff respect me as a whole person.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me
10. Mental health services have caused me emotional or physical harm.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me
11. I cannot get the services I need when I need them.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me

Please circle the response that best represents your situation *during the past six months*.

12. Mental health services helped me get medical benefits that meet my needs.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me
13. Mental health services led me to be more dependent, not independent.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me
14. I lack the information or resources I need to uphold my client rights and basic human rights.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me
15. I have enough income to live on.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me
16. Services help me develop the skills I need.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me

Section Two Directions: Please read each statement and then circle the response that best represents your situation *during the past six months*. The responses range from “Never/Rarely” to “Almost Always/Always.” If the statement was about something you did not experience, circle the last response “Does Not Apply To Me.”

17. I have housing that I can afford.	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does Not Apply To Me
18. I have a chance to advance my education if I want to.	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does Not Apply To Me
19. I have reliable transportation to get where I need to go.	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does Not Apply To Me
20. Mental health services helped me get or keep employment.	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does Not Apply To Me
21. Staff see me as an equal partner in my treatment program.	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does Not Apply To Me
22. Mental health staff support my self-care or wellness.	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does Not Apply To Me
23. I have a say in what happens to me when I am in crisis.	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does Not Apply To Me
24. Staff believe that I can grow, change and recover.	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does Not Apply To Me

Please circle the response that best represents your situation *during the past six months*.

25. Staff use pressure, threats, or force in my treatment.	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does Not Apply To Me
26. There was a consumer peer advocate to turn to when I needed one.	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does Not Apply To Me
27. There are consumers working as paid employees in the mental health agency where I receive services.	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does Not Apply To Me
28. Staff give me complete information in words I understand before I consent to treatment or medication.	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does Not Apply To Me
29. Staff encourage me to do things that are meaningful to me.	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does Not Apply To Me
30. Staff stood up for me to get the services and resources I needed.	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does Not Apply To Me
31. Staff treat me with respect regarding my cultural background (think of race, ethnicity, religion, language, age, sexual orientation, etc).	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does Not Apply To Me
32. Staff listen carefully to what I say.	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does Not Apply To Me
33. Staff lack up-to-date knowledge on the most effective treatments.	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does Not Apply To Me
34. Mental health staff interfere with my personal relationships.	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does Not Apply To Me
35. Mental health staff help me build on my strengths.	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does Not Apply To Me
36. My right to refuse treatment is respected.	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does Not Apply To Me
37. My treatment plan goals are stated in my own words.	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does Not Apply To Me
38. The doctor worked with me to get on medications that were most helpful for me.	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does Not Apply To Me

Please circle the response that best represents your situation *during the past six months*.

39. I am treated as a psychiatric label rather than as a person.	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does Not Apply To Me
40. I can see a therapist when I need to.	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does Not Apply To Me
41. My family gets the education or supports they need to be helpful to me.	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does Not Apply To Me
42. I have information or guidance to get the services and supports I need, both inside and outside my mental health agency.	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does Not Apply To Me

Section Three Directions: Are there other issues related to how services help or hinder your recovery? Please explain.

Section Four Directions: We are asking you to provide the following information in order for us to be able to have a general description of participants taking this survey. Please check the answer that best fits your response to the question or write in the answer in the line provided. Only answer those items you wish to answer. Please do not write your name or address on this survey. This keeps your identity confidential.

1. What is your gender? a. Female b. Male

2. What is your age? (Write your current age in the two boxes.)

3. What is your racial or ethnic background? (Check the one that applies best.)

- a. American Indian/ Alaska Native d. Native Hawaiian/ Other Pacific Islander f. More than one race
b. Asian e. White/Caucasian g. Other: _____
c. Black or African American

Do you consider yourself Hispanic or Latino/a? a. Yes b. No

4. Your level of education is: (Check the highest level you reached or currently are in.)

- a. Less than High School c. College/Technical Training e. Other: _____
b. High School/GED d. Graduate School

5. How long have you been receiving mental health services?

- a. Less than 1 year c. 3 to 5 years
b. 1 to 2 years d. More than 5 years

6. Which services have you used in the past six months? (Check all that apply.)

- a. Counseling/Psychotherapy e. Assertive Community Treatment (ACT) i. Case Management
b. Housing/Residential Services f. Psychosocial Rehabilitation j. Clubhouse
c. Medication Management g. Employment/Vocational Services k. Other: _____
d. Self-help/Consumer Run Service h. Alcohol/ Drug Abuse Treatment

[To survey administrator: Please collect this additional background information (if possible).]

7. The town, city or community you live in is mostly:

- a. Urban
- b. Suburban
- c. Rural
- d. Remote/Frontier

8. What type of place do you live in?

- a. Living in my own home or apartment
- b. Living in supervised/supported apartment
- c. Living in a residential facility
- d. Living in a boarding house
- e. Homeless or homeless shelter
- f. Other: _____

9. Are you a person who currently has both mental health and substance abuse (alcohol, drug addition) problems?

- a. Yes
- b. No

Appendix H:
ROSI 10 Item Self-Report Subset

Appendix H: ROSI 10 Item Self-Report Subset

Purpose: To provide the best possible mental health services, we want to know what things helped or hindered your progress during the past six (6) months. **Section One Directions:** Please read the statement and then circle the response that best represents your situation *during the last six months*. These responses range from strongly disagree to strongly agree. If the statement was about something you did not experience, circle the last response “Does not apply to me.”

1. There is at least one person who believes in me. (#1)	Strongly Disagree	Disagree	Agree	Strongly Agree	Does not apply to me
2. I am encouraged to use consumer-run programs (for example, support groups, drop-in centers, etc.). (#3)	Strongly Disagree	Disagr ee	Agree	Strongly Agree	Does not apply to me
3. Staff respect me as a whole person. (#9)	Strongly Disagree	Disagr ee	Agree	Strongly Agree	Does not apply to me
4. I do not have the support I need to function in the roles I want in my community. (#4)	Strongly Disagree	Disagree	Agree	Strongly Agree	Does not apply to me

Section Two Directions: Please read the statement and then circle the response that best represents your situation *during the last six months*. The responses range from never/rarely to almost always/always. If the statement was about something you did not experience, circle the last response “Does not apply to me.”

5. I have housing that I can afford. (#17)	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does not apply to me
6. Staff see me as an equal partner in my treatment program. (#21)	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does not apply to me
7. Mental health staff support my self-care or wellness. (#22)	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does not apply to me
8. I have a say in what happens to me when I am in crisis. (#23)	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does not apply to me
9. Staff believe that I can grow, change and recover. (#24)	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does not apply to me
10. Staff use pressure, threats, or force in my treatment. (#25)	Never/Rarely	Sometimes	Often	Almost Always/ Always	Does not apply to me

Appendix I:
Phase II Administrative-Based Item Survey Results

Appendix I: Phase II Administrative-Based Item Survey Results

The first number in each response category is the number of State Mental Health Authorities responding (N=9). The second number (below the first number) is the number of National Association of Consumer/Survivor Mental Health Administrators (NAC/SMHA) members responding (N=3).

Recovery Domain: Choice; Performance Indicator: Advanced Directives										
Measure 1: The percent of local mental health provider agencies that have a mechanism to help clients develop advance directives.										
Numerator: The # of local mental health provider agencies that have a mechanism to help clients develop advance directives.	VF	FF	LF	NF	VI	FI	LI	NI	Yes	No
Denominator: The total # of local mental health provider agencies.	2	2	2	2	4	2	2		1	7
	2	1			2	1			1	2
<p>This indicator is seen to be of limited importance to be collected at the state level but may be important at the provider level/managed care organization.</p> <p>But it's one thing to have a mechanism and another yet to actually use it. One could do a count of advance directives but that could get unwieldy. The SMHA has no policy requiring or recommending local mental health agencies to assist in the development of advanced directives. We do collect.</p> <p>Insufficient current policy at local level.</p> <p>DMH is currently developing this.</p> <p>Think this should be measured by program code not agency, that is, residential or community rehab support.</p> <p>State has developed a standard statewide advance directive.</p> <p>We can do both of these.</p>										
Measure 2: The percent of local mental health provider agencies that have a process for ensuring that advanced directives are followed.										
Numerator: The # of local mental health provider agencies that have a process for utilizing advanced directives	VF	FF	LF	NF	VI	FI	LI	NI	Yes	No
Denominator: The total # of local mental health provider agencies.	1	1	3	3	3	2	3		1	8
	2	1			2	1			1	2
<p>This indicator is seen to be of limited importance to be collected at the state level but may be important at the provider level/managed care organization.</p> <p>The SMHA maintain no records on advanced directives or their implementation.</p> <p>Insufficient current policy at local level.</p> <p>In process, see above.</p> <p>Think this should be measured by program code not agency.</p> <p>All public and private providers have received training on the use of the MH advanced directive.</p> <p>See Measure 1 response above.</p>										

How **feasible** is it for your agency to implement this measure? VF=Very Feasible FF=Fairly Feasible LF=Limited Feasibility NF=Not at all Feasible

How **important** is this information in fostering a recovery-orientation? VI=Very Important FI=Fairly Important LI=Limited Importance NI=Not at all Important

Are you currently **collecting** this information? Yes No

Recovery Domain: Choice; Performance Indicator: Involuntary Inpatient Commitments										
Measure: The percent of clients under involuntary inpatient commitments.										
Numerator: The # of clients who received involuntary inpatient commitments during the reporting period.	VF	FF	LF	NF	VI	FI	LI	NI	Yes	No
Denominator: The total # of clients who received inpatient services during the reporting period.	4	2	1	1	4	3	1		5	3
	3				1	1			2	
<p>This indicator is seen to be of limited importance to be collected at the state level but may be important at the provider level/managed care organization.</p> <p>No, But we have a new MIS coming on line soon that will track this event.</p> <p>We collect this data, but not as a performance indicator. We prefer outpatient commitments over inpatient commitments and track this for that reason – recognizing that voluntary treatment is most desirable.</p> <p>SMHA data is limited to state-operated hospitals only.</p> <p>Partial collection currently (state hospital only).</p> <p>Unknown if we are doing this.</p> <p>{Staff Member} keeps the data and does a semi-annual report.</p> <p>This is data is currently captured by our MIS.</p> <p>We can do this.</p>										

Recovery Domain: Choice; Performance Indicator: Involuntary Outpatient Commitments										
Measure: The percent of clients under involuntary outpatient commitments.										
Numerator: The # of clients who received involuntary outpatient commitments during the reporting period.	VF	FF	LF	NF	VI	FI	LI	NI	Yes	No
Denominator: The total # of clients who received outpatient services during the reporting period.	2	3	3		4	3	1		4	4
	2				1	1			1	
<p>This indicator is seen to be of limited importance to be collected at the state level but may be important at the provider level/managed care organization.</p> <p>As a requirement of enabling legislation the SMHA maintains records on involuntary outpatient commitments.</p> <p>Paper records.</p> <p>The denominator – from MH system, the numerator – from the Dept. of Criminal Justice. Therefore, two different data sets, may or may not match up.</p> <p>Unknown if we are doing this. Question mark.</p> <p>This is data is currently captured by our MIS.</p> <p>We can do this.</p>										

How **feasible** is it for your agency to implement this measure? VF=Very Feasible FF=Fairly Feasible LF =Limited Feasibility NF=Not at all Feasible
 How **important** is this information in fostering a recovery-orientation? VI=Very Important FI=Fairly Important LI=Limited Importance NI=Not at all Important
 Are you currently **collecting** this information? Yes No

Recovery Domain: Peer Support; Performance Indicator: Peer-Operated Services Funding										
Measure 1: The percent of state program funds allocated for peer-operated services. Numerator: The amount of funds in the state mental health budget allocated for peer-operated services during the reporting period. Denominator: The total amount of funds in state mental health budget during the reporting period.	VF	FF	LF	NF	VI	FI	LI	NI	Yes	No
	3	2	2		5	3			4	4
	3				2	1			1	1
<p>This may involve detailed accounting of funds since funded programs may include peer-operated services as only one of its many components. This poses problems in data accuracy.</p> <p>Not in current data systems – change would be very costly. Also consumers often do not “sign-in” for peer services.</p> <p>The denominator should be operating funds only, not to include capital budget or debt service.</p> <p>We do not currently fund any peer-operated services but hope to in the near future.</p> <p>Need clearer definition of “peer-operated.” Traditional peer-operated services only or general services delivered by consumer-providers? Unknown if we are doing this.</p> <p>Too broad using the state MH budget. By area funds are easier to obtain.</p> <p>This is available and the state MH plan posted on the OMH website.</p> <p>Unfortunately we won’t be able to report either of these. Our funding goes out in block-grant type payments. But we could report on Peer- operated services delivered.</p>										
Measure 2: The percent of Medicaid funding used for peer-operated services. Numerator: The amount of Medicaid reimbursement for services delivered in peer-operated programs during the reporting period. Denominator: The total amount of Medicaid reimbursement for behavioral health care during the reporting period.	VF	FF	LF	NF	VI	FI	LI	NI	Yes	No
	1	1	3	2	4	1		2	1	7
	1		1		1	1			1	
<p>Feasibility of collecting data at the state level is very low due to detailed accounting required.</p> <p>The Medicaid agency is separate from our department but they do not fund any peer-operated services.</p> <p>No Medicaid funding used for this purpose.</p> <p>Need clearer definition of “peer-operated.” Traditional peer-operated services only or general services delivered by consumer-providers? Unknown if we are doing this. Question mark.</p> <p>Is posted as above.</p> <p>See Measure 2 above.</p>										

How **feasible** is it for your agency to implement this measure? VF=Very Feasible FF=Fairly Feasible LF=Limited Feasibility NF=Not at all Feasible
How **important** is this information in fostering a recovery-orientation? VI=Very Important FI=Fairly Important LI=Limited Importance NI=Not at all Important
Are you currently **collecting** this information? Yes No

Recovery Domain: Peer Support; Performance Indicator: Consumer Employment within Mental Health Systems										
Measure 1: The percent of direct care service staff who are former or current disclosed consumers. Numerator: The # of direct care staff (unduplicated) who are disclosed consumers (former or current) during the reporting period. Denominator: The total # of direct care staff (unduplicated) during the reporting period.	VF	FF	LF	NF	VI	FI	LI	NI	Yes	No
		2	3	3	1	4	2	1		8
			1	2		3				2
<p>The SMHA has no database or policies regarding private local agencies hiring consumers.</p> <p>What does former mean? Someone may have formerly disclosed but not disclosing now. Privacy issues.</p> <p>Depends on definition of “consumer.” If consumer means willingness to self-disclose his/her status, then it would be possible.</p> <p>ADA limits the data collection. I know this would be useful but it pre-supposed (a) people have to have identified with the label ‘consumer’ at one time and (b) voluntary disclose – taboo.</p> <p>By program code – if it is only feasible to collect disclosed consumers is this a valid measure?</p> <p>We won’t know this at the state level. Will have to ask providers to report.</p>										
Measure 2: There are programs/institutes specifically designed to train consumers to become mental health providers. (Yes/No)	VF	FF	LF	NF	VI	FI	LI	NI	Yes	No
	3	2	1	2	4	3		1	2	6
	1		1		1	1				2
<p>There is only one program statewide for this so it’s sort of too easy to measure.</p> <p>We do not have any currently but are in the process of developing Peer Specialist Training.</p> <p>Resources too limited.</p> <p>Last one skipped.</p> <p>Needs to be more specific than MH provider.</p> <p>Last one only one completed.</p> <p>We can do this one.</p>										

Recovery Domain: Formal Services (System Orientation); Performance Indicator: Recovery Oriented Mission Statement										
Measure 1: The state mental health authority’s mission statement includes a recovery orientation. (Yes/No)	VF	FF	LF	NF	VI	FI	LI	NI	Yes	No
	7	1			6	2			5	3
	1				2				3	
<p>We questioned who decides the mission statement is inclusive of recovery principles. Our mission statement globally addresses recovery but not specifically.</p> <p>SMHA does.</p> <p>SMHA does.</p> <p>Last one only one completed.</p> <p>We can do this.</p>										

How **feasible** is it for your agency to implement this measure? VF=Very Feasible FF=Fairly Feasible LF=Limited Feasibility NF=Not at all Feasible
How **important** is this information in fostering a recovery-orientation? VI=Very Important FI=Fairly Important LI=Limited Importance NI=Not at all Important
Are you currently **collecting** this information? Yes No

Measure 2: The percent of local mental health provider agencies whose mission statements include a recovery orientation. Numerator: The # of local mental health provider agencies whose mission statement includes a recovery orientation. Denominator: The total # of local mental health provider agencies.	VF 3 2	FF 3 1	LF 1 1	NF 1 1	VI 4 2	FI 3 1	LI 1 1	NI	Yes	No 8 3
The SMHA has no mission statement data from local provider agencies. Only fairly feasible because of ambiguity – i.e., do mission statement need to include the word “recovery” to be recovery-oriented? Can only address DMH provider. Should be part of every contract. We can do this.										

Recovery Domain: Formal Services (System Orientation); Performance Indicator: Consumer Specified Outcomes										
Measure: The percent of provider agency performance contracts that have primary consumer specified outcomes. Numerator: The # of provider agency performance contracts documenting primary consumer involvement in and specification of service contract outcomes. Denominator: The total # of provider agency performance contracts.	VF 2 2	FF 2 1	LF 1 1	NF 2 2	VI 4 2	FI 1 1	LI 2 2	NI	Yes 2 2	No 4 1
Provider agency is limited to state subcontractors only (i.e., managed care organizations). We contract for Number of persons to be served but not clinical outcomes. Use performance incentives with dollars instead. No statewide or local data is available on consumer specified outcomes. Unclear question, did not respond. Moving forward on this. Not applicable now. If this means the state’s contracts with local MHAs then it is feasible but not very meaningful. If this means local mental health agencies’ contracts with providers outside the system, then not feasible. Resistance to creating such indicators, talk of agreement as to what they are. Just beginning to look at percentage of clients as one. Need to be clearer. Some exist. What is being specifically looked for? We can do this for our regional support networks.										

Recovery Domain: Formal Services (System Orientation); Performance Indicator: Office of Consumer Affairs										
Measure 1: The percent of staff in the State Office of Consumer Affairs who are former or current consumers. Numerator: The # State Office of Consumer Affairs staff (unduplicated) who are disclosed consumers (former or current) during the reporting period. Denominator: The total # of State Office of Consumer Affairs staff (unduplicated) during the reporting period.	VF 8 2	FF	LF	NF	VI 5 2	FI 2	LI 1	NI	Yes 5 1	No 3 1

How **feasible** is it for your agency to implement this measure? VF=Very Feasible FF=Fairly Feasible LF=Limited Feasibility NF=Not at all Feasible
How **important** is this information in fostering a recovery-orientation? VI=Very Important FI=Fairly Important LI=Limited Importance NI=Not at all Important
Are you currently **collecting** this information? Yes No

Number of family members is important too.
 Only in person in state, so limited importance here, but may be important in other states.
 There is one state person with an assistant, one regional (area) person and 7 other site people unevenly distributed. The consumer status is a pre-requisite for hire.
 N/A to the area.
 State currently has no state office of consumer affairs.
 We can do these, but it seems like there are a lot of these.

Measure 2: The percent of regional mental health offices/local mental health authorities (or equivalent) that have an Office of Consumer Affairs. Numerator: The # of regional mental health offices/local mental health authorities (or equivalent) that have an Office of Consumer Affairs during the reporting period. Denominator: The total # of regional mental health offices/local mental health authorities (or equivalent) during the reporting period.	VF 3 3	FF 1	LF 2	NF	VI 3 3	FI 2	LI 1	NI	Yes 1 1	No 5 2
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Only one large city and one wealthy county have a local Office of Consumer Affairs.
 Not applicable - we do not have regional or local MHAs.
 This would be an excellent indicator!
 N/A to area unless reframed.
 State currently has no office of consumer affairs.
 See response to Measure 1 above.

Measure 3: The percent of central office administrative budget allocated to the State Office of Consumer Affairs. Numerator: The amount of funds in the central office administrative budget allocated to the State Office of Consumer Affairs during the reporting period. Denominator: The total amount of funds in central office administrative budget during the reporting period.	VF 5 2	FF 2	LF 1	NF	VI 4 2	FI 1	LI 3	NI	Yes 1 1	No 7 1
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State does collect.
 Excellent indicator! Easy information to get, though.
 N/A
 \$0.00
 See response to Measure 1 above.

How **feasible** is it for your agency to implement this measure? VF=Very Feasible FF=Fairly Feasible LF=Limited Feasibility NF=Not at all Feasible
 How **important** is this information in fostering a recovery-orientation? VI=Very Important FI=Fairly Important LI=Limited Importance NI=Not at all Important
 Are you currently **collecting** this information? Yes No

Recovery Domain: Formal Services (System Orientation); Performance Indicator: Consumer Inclusion in Governance and Policy										
<p>Measure 1: The percent of the state planning council membership that are primary consumers. Numerator: The # of primary consumers (unduplicated) who are state planning council members during the reporting period. Denominator: The total # state planning council members (unduplicated) during the reporting period.</p>	VF 7 2	FF 1	LF	NF	VI 8 2	FI	LI	NI	Yes 7 2	No 1
<p>Family members are important too. Who defines “Consumer?” Is there a standard definition or does each MHA define it? Important but only if state planning council is more than an after thought/vestigial body. Question mark. Can do.</p>										
<p>Measure 2: The percent of local mental health provider agencies that mandate participation of primary consumers on their governing boards. Numerator: The # of local mental health provider agencies that mandate participation of primary consumers on their governing boards. Denominator: The total # local mental health provider agencies with governing boards.</p>	VF 2 3	FF 4	LF 2	NF	VI 2 3	FI 6	LI	NI	Yes 1	No 8 2
<p>Local governing board data on consumer participation is unavailable. We suggest the term “membership” rather than participation to ensure the consumer is a voting member. Also, there is no indicator for State governing boards. Would need to survey. Again, is “consumer” limited to a person who is willing to reveal his/her status? This would be an excellent indicator! This is a part of philosophy but data is not collected. It could be. For DMH provider only. State collects. Can do.</p>										
<p>Measure 3: The percent of the local mental health provider agency board membership that are primary consumers. Numerator: The # of primary consumers (unduplicated) who serve on local mental health provider agency boards during the reporting period. Denominator: The total # local mental health provider agency board members (unduplicated) during the reporting period.</p>	VF 2 1	FF 4 1	LF 2	NF	VI 2 2	FI 6	LI	NI	Yes	No 8 2

How **feasible** is it for your agency to implement this measure? VF=Very Feasible FF=Fairly Feasible LF=Limited Feasibility NF=Not at all Feasible
How **important** is this information in fostering a recovery-orientation? VI=Very Important FI=Fairly Important LI=Limited Importance NI=Not at all Important
Are you currently **collecting** this information? Yes No

Statewide data on consumer participation in local governing boards is unavailable.
 We suggest the term “membership” rather than participation to ensure the consumer is a voting member. Also, there is no indicator for State governing boards.
 Would need to survey. Again, is “consumer” limited to a person who is willing to reveal his/her status?
 Another excellent indicator! Should be at least 50%. Since many individuals cannot make every meeting – ensures more than one or two at each meeting and avoids tokenism!
 This is a part of state philosophy but data is not collected. It could be. For DMH provider only.
 Can’t do.

Measure 4: The state mental health authority directly involves primary consumers with policy development and review. Numerator: The # of polices in the denominator (unduplicated) reviewed by primary consumers prior to the public comment period. Denominator: The total # of new polices and current policies with proposed revision (unduplicated) released for public comment during the reporting period.	VF 2 1	FF 2	LF 3	NF 2	VI 4 2	FI 2	LI 2	NI	Yes 1	No 8 1
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State does not have a policy manual per se. Policy decisions are made with Planning Council input – but we would have no numbers for this measure.
 SMHA data on consumer participation in policy review and development is not available.
 “Policy” is such an inclusive term we were not sure what could be included in this measure.
 Would need to survey. Again, is “consumer” limited to a person who is willing to reveal his/her status?
 Excellent and very feasible indicator!
 Should be standard practice, but not a measure.
 State collects.
 This one is going to be difficult for most states to track, I think.

Recovery Domain: Formal Services - Coercion; MHSIP’s Proposed Indicator On Seclusion										
Measure 1: Hours of seclusion as a percent of client hours. Numerator: The total # of hours that all clients spent in seclusion. Denominator: Sum of the daily census (<u>excluding</u> clients on leave status) for each day (client days) multiplied by 24 hours.	VF 6 2	FF 1 1	LF	NF 1	VI 7 2	FI 1 1	LI	NI	Yes 6 2	No 2

How **feasible** is it for your agency to implement this measure? VF=Very Feasible FF=Fairly Feasible LF=Limited Feasibility NF=Not at all Feasible
 How **important** is this information in fostering a recovery-orientation? VI=Very Important FI=Fairly Important LI=Limited Importance NI=Not at all Important
 Are you currently **collecting** this information? Yes No

Measure should be the same as reported for ORYX to decrease burden and increase comparability – if so, okay.
 Data available for state-operated hospitals only.
 Coercion is more than seclusion and restraint. There are medication coercion and getting kicked out of housing if not participating in day treatment.
 Perhaps a measure of “basic needs” tied into compliance with treatment recommendations?
 Add “inpatient” to measure.
 For state hospital only.
 Unknown if collect.
 Can do.

Measure 2: Percent of clients secluded at least once during a reporting period. Numerator: The total # of clients (unduplicated) who were secluded at least once during a reporting period. Denominator: The total # of unduplicated clients who were inpatients at the facility during a reporting period.	VF 7 3	FF	LF	NF 1	VI 7	FI 1 2	LI	NI	Yes 7 2	No 1
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Measure should be the same as reported for ORYX to decrease burden and increase comparability – if so, okay.
 Data available for state-operated hospitals only.
 For state hospital only.
 Unknown if collect.
 Can do.

Recovery Domain: Formal Services - Coercion; MHSIP’s Proposed Indicator On Restraints

Measure 1: Hours of restraint as a percent of client hours. Numerator: The # # of hours that all clients spent in restraint during a reporting period. Denominator: Sum of the daily census (<u>excluding</u> clients on leave status) for each day in a reporting period (client days) multiplied by 24 hours.	VF 7 3	FF	LF	NF 1	VI 7 3	FI 1	LI	NI	Yes 7 3	No 1
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Measure should be the same as reported for ORYX to decrease burden and increase comparability – if so, okay.
 Data available for state-operated hospitals only.
 “Inpatient” needs to be added to the measure.
 For state hospital only.
 Can do.

Measure 2: Percent of clients restrained at least once during the reporting period. Numerator: The # # of clients (unduplicated) who were restrained at least once during a reporting period. Denominator: The # # of unduplicated clients who were inpatients at the facility during the reporting period.	VF 7 3	FF	LF	NF 1	VI 7 3	FI 1	LI	NI	Yes 6 3	No 1
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How **feasible** is it for your agency to implement this measure? VF=Very Feasible FF=Fairly Feasible LF=Limited Feasibility NF=Not at all Feasible
 How **important** is this information in fostering a recovery-orientation? VI=Very Important FI=Fairly Important LI=Limited Importance NI=Not at all Important
 Are you currently **collecting** this information? Yes No

Measure should be the same as reported for ORYX to decrease burden and increase comparability – if so, okay.
 Data available for state-operated hospitals only.
 For state hospital only.
 Can do.)

Recovery Domain: Formal Services; *Additional measure for MHSIP's Proposed Indicator on Medication Errors*

Measure: The percent of clients whose total dosage of medication exceeds established clinical parameters.										
Numerator?	VF	FF	LF	NF	VI	FI	LI	NI	Yes	No
Denominator?	1	1	2	4	2	4	2		1	7

Current state of reporting medication errors will pose a problem in data collection. You might want to reconsider the measure that is consistent with the NASMHPD ORYX Indicator. Proposed measure is unwieldy.
 Data unavailable.
 If EMR – just recently beginning to look at available data.
 Limited usefulness do to incredible variability on med dosages - people can be within their clinical dosage norms and still be overmedicated according to their individual needs/metabolism/side effect profile. Unknown if collect.
 Med errors is a U.R. standard. It is usually self-reporting or found in chart review. Different types of errors. The measure if dosage is purposeful would only be found in PNS.
 State collects.
 We can do for state hospitals, but not for the community. I'm guessing most states are in the same boat on this one.

Recovery Domain: Formal Services; *Additional measure for MHSIP's Proposed Indicator on Involvement in the Criminal Justice/Juvenile Justice System*

Measure: The percent of mental health catchment/service areas that have jail diversion services.										
Numerator: Total # of mental health catchment/service areas that have jail diversion services.	VF	FF	LF	NF	VI	FI	LI	NI	Yes	No
Denominator: Total # of mental health catchment/service areas.	7	1			7	1			4	4
	3				2	1			1	2

Data is available at the state subcontractors level only (i.e., managed care organizations).
 Information is not a performance indicator.
 Not all CMHCs have them.
 Need clearer definition of “jail diversion services.”
 Can go either way, does percentage mean good services (decrease in the prison population) or more effective police- state function of the MHA?
 Can do.

How **feasible** is it for your agency to implement this measure? VF=Very Feasible FF=Fairly Feasible LF=Limited Feasibility NF=Not at all Feasible
 How **important** is this information in fostering a recovery-orientation? VI=Very Important FI=Fairly Important LI=Limited Importance NI=Not at all Important
 Are you currently **collecting** this information? Yes No

Recovery Domain: Formal Services; <i>Additional measure for MHSIP's Proposed Indicator on Services in the Least Restrictive Service Setting</i>										
Measure: The percent of contacts made by mental health agency staff to clients that occurred outside of the office.										
Numerator: Total # of contacts by the mental health agency to clients that occurred outside the office during the reporting period.	VF	FF	LF	NF	VI	FI	LI	NI	Yes	No
Denominator: Total # of contacts by the mental health agency to clients during the reporting period.	2	2	3	3	4	3	1		1	7
We were able to measure this until HIPAA implementation and now we do not have a way to tie location and service together. The worse case managers still meet clients in the field. Needs to be additional indicators, e.g., consumer satisfaction survey after every encounter? To be able to capture this data, it needs to be more specific and separate out C/A. State collects. We can do this.										

Recovery Domain: Formal Services; <i>Additional measure for MHSIP's Proposed Indicator on Reduced Substance Abuse Impairment</i>										
Measure: The percent of mental health catchment/service areas that have integrated substance abuse and mental health services.										
Numerator: Total # of mental health catchment/service areas that have integrated substance abuse and mental health services.	VF	FF	LF	NF	VI	FI	LI	NI	Yes	No
Denominator: Total # of mental health catchment/service areas.	1	5	1		7	1			1	7
We will be collecting this information in about 6 months. Separate adults from adolescents. We are afraid "integrated" can be misinterpreted, e.g., both services occur under the same roof. Need fidelity measures for this. This needs further definition. What does integrated SA and MH services mean? Everyone is screened for both and referred or there is a Dual Recovery Anonymous meeting that meets weekly in the area to which clients can go if they want to? Unknown if collect. Too broad, I think. Each would say yes. Need to hook it up with population somehow. Can't measure using new HIPAA service codes.										

Recovery Domain: Formal Services (Trauma Services); Performance Indicator: Trauma Service Provision										
Measure: The percent of clients that receive trauma services.										
Numerator: The # of persons, 18 and older, with severe mental illness receiving trauma services (unduplicated) during the reporting period.	VF	FF	LF	NF	VI	FI	LI	NI	Yes	No
Denominator: Total # of persons served in the community, 18 and older, with a serious mental illness (Unduplicated).	1	1	2	4	5	3				8
	2				2					2

How **feasible** is it for your agency to implement this measure? VF=Very Feasible FF=Fairly Feasible LF=Limited Feasibility NF=Not at all Feasible
How **important** is this information in fostering a recovery-orientation? VI=Very Important FI=Fairly Important LI=Limited Importance NI=Not at all Important
Are you currently **collecting** this information? Yes No

Unless trauma services are specifically defined, this may not be feasible.
 Not in data systems.
 We were not sure how to identify “trauma” services for other clinical services.
 Define trauma services.
 Most important indicator in my opinion.
 This is captured by the partnership.
 Need a definition of what trauma services are, and I’m guessing they will be difficult to measure using the new HIPAA service codes.

Recovery Domain: Formal Services (Stigma and Discrimination); Performance Indicator: General Public Education and Awareness Campaigns										
Measure: The percent of state mental health budget funds earmarked for public awareness education, prevention, and/or wellness campaigns.										
Numerator: The amount of funds in the state mental health budget allocated for public awareness education, prevention, and/or wellness campaigns during the reporting period.	VF 1	FF 2	LF 5	NF	VI 3	FI 3	LI 2	NI	Yes 1	No 7
Denominator: The total amount of funds in the state mental health budget during the reporting period.	2	1			1		1		2	
<p>This indicator may be difficult to measure because public awareness education, prevention, and/or wellness campaigns are inherently part of other services provided, e.g. case management. Money not specifically allocated for this, nor tracked in data systems. No, except for specific initiatives. Easy to measure because no funds earmarked. Public relations does not make recovery outcomes. This won’t capture what you are looking for or give you the total picture because there is a fair amount of integration with other agencies and affiliations, i.e., Dept of Public Health, NAMI. Can do, but most of this is done through contract with other advocacy organizations, not as direct spend.</p>										

Recovery Domain: Formal Staff; Additional measure for MHSIP’s Proposed Indicator on Cultural Competence										
Measure: The direct care staff race/ethnicity demographics as compared to client race/ethnicity demographics within each local mental health provider agency.										
Numerator?	VF 2	FF 3	LF 3	NF	VI 4	FI 3	LI 1	NI	Yes 2	No 6
Denominator?	1				1				1	

How **feasible** is it for your agency to implement this measure? VF=Very Feasible FF=Fairly Feasible LF=Limited Feasibility NF=Not at all Feasible
 How **important** is this information in fostering a recovery-orientation? VI=Very Important FI=Fairly Important LI=Limited Importance NI=Not at all Important
 Are you currently **collecting** this information? Yes No

This indicator may not give a one to one correspondence of staff-client racial/ethnicity comparison but globally.
 Demographic data on local provider staff is not reported to the SMHA.
 State does collect it.
 Needs to include gender.
 Working on this measure.
 Missing this page.
 It is done with the DMH staffing. I am not sure of providers.
 State collects.
 We can't do this at the state level. We do not have any information on individual clinicians.

Recovery Domain: Formal Staff; Performance Indicator: Direct Care Staff to Client Ratio

Measure: The ratio of direct care staff to clients within each local mental health service contractor.										
Numerator: The total # of direct care staff (unduplicated) during the reporting period.	VF	FF	LF	NF	VI	FI	LI	NI	Yes	No
Denominator: The total # of clients (unduplicated) during the reporting period.	2	5		1	3	5			1	7
	1				1				1	

State does collect it.
 No, but have done it on occasion.
 Missing this page.
 Part of contract.
 State collects.
 This would have to be reported by providers.

Other Comments:

How **feasible** is it for your agency to implement this measure? VF=Very Feasible FF=Fairly Feasible LF=Limited Feasibility NF=Not at all Feasible
 How **important** is this information in fostering a recovery-orientation? VI=Very Important FI=Fairly Important LI=Limited Importance NI=Not at all Important
 Are you currently **collecting** this information? Yes No

Appendix J:
ROSI Administrative-Data Profile

Appendix J: ROSI Administrative-Data Profile

Recovery Oriented System Indicators (ROSI) Administrative-Data Profile

Recovery Theme: Peer Support (involves the findings that peer support and consumer operated services in a myriad of forms facilitates recovery).

- 1: Independent Peer/Consumer Operated Programs
The percentage of mental health catchment or service areas responding that have independent peer/consumer operated programs.
- 2: Peer/Consumer Delivered Service Funding
For the reporting period, the percentage of state program funds allocated for peer/ consumer delivered services.
- 3: Medicaid Funded Peer/Consumer Delivered Services.
For the reporting period, the percentage of Medicaid funding reimbursed for peer/consumer delivered services.
- 4: Consumer Employment in Mental Health Systems
The number of annual slots specifically funded for training primary consumers in relevant educational and training programs and institutes to become mental health providers.
- 5: Affirmative Action Hiring Policy
The percentage of local mental health provider agencies responding that have an affirmative action hiring policy regarding primary consumers.

Recovery Theme: Choice (involves the findings that having choices, as well as support in the process of making choices, regarding housing, work, social, service, treatment as well as other areas of life facilitate recovery).

- 6: Advance Directives
The percentage of local mental health provider agencies responding that have an established mechanism to help clients develop advance directives.

Recovery Theme: Formal Service Staff (involves the findings as to the critical roles formal service staff play in helping or hindering the recovery process).

- 7: Direct Care Staff to Client Ratio
For the reporting period, the ratio of direct care staff to clients for all local mental health provider agencies responding.

Recovery Theme: Formal Services (involves the findings that formal service systems' culture, organization, structure, funding, access, choice, quality, range, continuity and other characteristics can help or hinder the process of recovery).

Formal Services Sub-Theme: Helpful System Culture and Orientation (involves the finding that a formal service system's culture and orientation that is holistic and consumer oriented facilitates recovery).

8. State Recovery Oriented Mission Statement
The state mental health authority's mission statement explicitly includes a recovery orientation.
9. Local Agency Recovery Oriented Mission Statement
The percentage of local mental health provider agencies responding whose mission statements explicitly include a recovery orientation.
10. Consumer Involvement in Provider Contract Development
The percentage of provider agency performance contracts reported that have primary consumer involvement in their development/yearly review (i.e., specifying services, outcomes, target numbers, etc).
11. State Office of Consumer Affairs
For the reporting period, the percentage of staff in the state office of consumer affairs who are primary disclosed consumers.
12. Regional/Local Office of Consumer Affairs
For the reporting period, the percentage of regional mental health offices/local mental health authorities (or equivalent) responding that have an office of consumer affairs.
13. Consumer Representation on State Planning Council
For the reporting period, the percentage of state mental health authority planning council members who are disclosed primary consumers.
- 14: Consumer Representation on Local Boards
For the reporting period, the percentage of board membership that are disclosed primary consumers of local mental health provider agencies responding.

Formal Services Sub-Theme: Coercion (involves the finding that coercion in formal service systems hinders recovery).

15. Involuntary Inpatient Commitments
For the reporting period, the percentage of involuntary admissions in the public and private inpatient units responding.
16. Involuntary Outpatient Commitments
For the reporting period, the percentage of clients (unduplicated) under involuntary outpatient commitments of the local mental health provider agencies responding.
17. Seclusion Hours
For the reporting period, the hours of seclusion as a percentage of client hours of the units responding.
18. Seclusion of Clients
For the reporting period, the percentage of clients secluded at least once of the units responding.

19. Restraint Hours

For the reporting period, the hours of restraint as a percentage of client hours of the units responding.

20. Restraint of Clients

For the reporting period, the percentage of clients restrained at least once of the units responding.

Formal Services Sub-Theme: Access to Services (involves the findings as to getting the formal services that consumers feel they need and find helpful facilitates recovery).

21. Diversion from Criminal/Juvenile Justice Systems

The percentage of mental health catchment or service areas responding that have jail diversion services.

22. Integrated Substance Abuse and Mental Health Services

The percentage of mental health catchment or service areas responding that have integrated substance abuse and mental health services.

23. Trauma Service Provision

The percentage of mental health catchment or service areas responding that have trauma services.

ROSI Administrative-Data Profile: Authority Characteristics

Authority: _____ Date _____

1. What is your organization's legal structure?

- a. Public
b. Private Nonprofit
c. Private for Profit
d. Other: _____

2. Geographic Location:

Country: _____

State/ Province: _____

3. What geographic area do you cover?

4. Geographic Setting (check all that apply):

- a. Urban
b. Small City
c. Suburban
d. Rural
e. Remote/Frontier

5. How many providers of mental health services are in your network (unduplicated)?

6. How many providers of mental health services are in your network provided data for this ROSI Administrative-Data Profile?

7. What populations do you serve? (Check all that apply.)

- a. Children General Mental Health
b. Adult General Mental Health
c. Elderly General Mental Health
d. Children Serious Emotional Disord
e. Adult Serious Mental Illness
f. Elderly Serious Mental Illness
g. Children Substance Abuse
h. Adult Substance Abuse
i. Other: _____

Thank You!

ROSI Administrative Data Profile – Authority Level

Directions: Please respond to each item as thoroughly as possible. Please report data for your current activities or your most recently completed fiscal year. When the available data does not fully meet the specified item definition, please define the data used for that item on the form and continue to the next item. When data is not available, please indicate this on the form and continue to the next item.

1. Independent Peer/Consumer Operated Programs

1a. Numerator: The total number of mental health catchment or service areas responding that have independent peer/consumer operated programs:

1a. _____

1b. Denominator: The total number of mental health catchment or service areas responding:

1b. _____

1c. Indicator: The percentage of mental health catchment or service areas responding that have independent peer/consumer operated programs.

(Numerator 1a. divided by denominator 1b.)

1c. _____ %

2. Peer/Consumer Delivered Service Funding

2a. Numerator: For the reporting period, the amount of program funds in the state mental health budget allocated for peer/consumer delivered services:

2a. _____

2b. Denominator: For the reporting period, the total amount of program funds in state mental health budget:

2b. _____

2c. Indicator: For the reporting period, the percentage of state program funds allocated for peer/consumer delivered services.

(Numerator 2a. divided by denominator 2b.)

2c. _____ %

3. Medicaid Funded Peer/Consumer Delivered Services.

3a. Numerator: For the reporting period, the amount of Medicaid reimbursement for services delivered in peer/consumer operated programs and by peer specialists.

3a. _____

3b. Denominator: For the reporting period, the total amount of Medicaid reimbursement for behavioral health care.

3b. _____

3c. Indicator: For the reporting period, the percentage of Medicaid funding reimbursed for peer/consumer delivered services.

(Numerator 3a. divided by denominator 3b.)

3c. _____ %

4. Consumer Employment in Mental Health Systems

4. Indicator: The number of annual slots specifically funded for training primary consumers in relevant educational and training programs and institutes to become mental health providers.

Number of Annual Slots

4. _____

5. Affirmative Action Hiring Policy

5a. Numerator: The number of local mental health provider agencies responding that have an affirmative action hiring policy regarding primary consumers.

5a. _____

5b. Denominator: The total number of local mental health provider agencies responding.

5b. _____

5c. Indicator: The percentage of local mental health provider agencies responding that have an affirmative action hiring policy regarding primary consumers. (Numerator 5a. divided by denominator 5b.)

5c. _____ %

6. Advance Directives

6a. Numerator: The number of local mental health provider agencies responding that have an established mechanism to help clients develop advance directives.

6a. _____

6b. Denominator: The total number of local mental health provider agencies responding. (Note: Same as 5b)

6b. _____

6c. Indicator: The percentage of local mental health provider agencies responding that have an established mechanism to help clients develop advance directives. (Numerator 6a. divided by denominator 6b.)

6c. _____ %

7. Direct Care Staff to Client Ratio

7a. Numerator: For the reporting period, the total number of direct care staff (unduplicated) of local mental health provider agencies responding.

7a. _____

7b. Denominator: For the reporting period, the total number of clients (unduplicated) of local mental health provider agencies responding.

7b. _____

7c. Indicator: For the reporting period, the ratio of direct care staff to clients for all local mental health provider agencies responding. (Numerator 7a to denominator 7b.)

7c. _____

8. State Recovery Oriented Mission Statement

8. Indicator: The state mental health authority's mission statement explicitly includes a recovery orientation.

Yes No

If yes, please describe the initiatives for implementing this recovery orientation:

9. Local Agency Recovery Oriented Mission Statement

9a. Numerator: The number of local mental health provider agencies responding whose mission statement includes a recovery orientation.

9a. _____

9b. Denominator: The total number of local mental health provider agencies responding.

(Note: Same as 5b)

9b. _____

9c. Indicator: The percentage of local mental health provider agencies responding whose mission statements explicitly include a recovery orientation.

(Numerator 9a. divided by denominator 9b.)

9c. _____ %

10. Consumer Involvement in Provider Contract Development

10a. Numerator: The number of authority level provider agency performance contracts reported that document primary consumer involvement in their development/yearly review.

10a. _____

10b. Denominator: The total number of authority level provider agency performance contracts reported.

10b. _____

10c. Indicator: The percentage of authority level provider agency performance contracts reported that have primary consumer involvement in their development/yearly review (i.e., specifying services, outcomes, target numbers, etc).

(Numerator 10a. divided by denominator 10b.)

10c. _____ %

11. State Office of Consumer Affairs

11a. Numerator: For this reporting period, the number of staff (unduplicated) in the state office of consumer affairs who are disclosed primary consumers.

11a. _____

11b. Denominator: For this reporting period, the total number of staff (unduplicated) in the state office of consumer affairs.

11b. _____

11c. Indicator: For the reporting period, the percentage of staff in the state office of consumer affairs who are primary disclosed consumers.

(Numerator 11a. divided by denominator 11b.)

11c. _____ %

12. Regional/Local Office of Consumer Affairs

12a. Numerator: For this reporting period, the number of regional mental health offices/local mental health authorities (or equivalent) responding that have an office of consumer affairs.

12a. _____

12b. Denominator: For this reporting period, the total number of regional mental health offices/local mental health authorities (or equivalent) responding.

12b. _____

12c. Indicator: For the reporting period, the percentage of regional mental health offices/ local mental health authorities (or equivalent) responding that have an office of consumer affairs.

(Numerator 12a. divided by denominator 12b.)

12c. _____ %

13. Consumer Representation on State Planning Council

13a. Numerator: For the reporting period, the number of disclosed primary consumers (unduplicated) who are state planning council members.

13a. _____

13b. Denominator: For the reporting period, the total number state planning council members (unduplicated).

13b. _____

13c. Indicator: For the reporting period, the percentage of state mental health authority planning council members who are disclosed primary consumers.

(Numerator 13a. divided by denominator 13b.)

13c. _____ %

14: Consumer Representation on Local Boards

14a. Numerator: For the reporting period, the number of disclosed primary consumers (unduplicated) who serve on boards of local mental health provider agencies responding.

14a. _____

14b. Denominator: For the reporting period, the total number board members (unduplicated) of local mental health provider agencies responding.

14b. _____

14c. Indicator: For the reporting period, the percentage of board membership that are disclosed primary consumers of local mental health provider agencies responding.

(Numerator 14a. divided by denominator 14b.)

14c. _____ %

15. Involuntary Inpatient Commitments

15a. Numerator: For the reporting period, the number of involuntary inpatient admissions in the public and private inpatient units responding.

15a. _____

15b. Denominator: For the reporting period, the total number of inpatient admissions in the public and private inpatient units responding.

15b. _____

15c. Indicator: For the reporting period, the percentage of involuntary admissions in the public and private inpatient units responding.

(Numerator 15a. divided by denominator 15b.)

15c. _____%

16. Involuntary Outpatient Commitments

16a. Numerator: For the reporting period, the number of clients (unduplicated) on involuntary outpatient commitment status (new and continuing) of the local mental health provider agencies responding.

16a. _____

16b. Denominator: For the reporting period, the total number of clients (unduplicated) who received outpatient services from the local mental health provider agencies responding.

16b. _____

16c. Indicator: For the reporting period, the percentage of clients (unduplicated) under involuntary outpatient commitments of the local mental health provider agencies responding.

(Numerator 16a. divided by denominator 16b.)

16c. _____%

17. Seclusion Hours

17a. Numerator: For the reporting period, the total number of hours that all clients spent in seclusion at the inpatient units responding.

17a. _____

17b. Denominator: For the reporting period, the sum of the daily census (excluding clients on leave status) for each day (client days) multiplied by 24 hours for the inpatient units responding.

17b. _____

17c. Indicator: For the reporting period, the hours of seclusion as a percentage of client hours for the inpatient units responding.

(Numerator 17a. divided by denominator 17b.)

17c. _____%

18. Seclusion of Clients

18a. Numerator: For the reporting period, the total number of clients (unduplicated) who were secluded at least once in the inpatient units responding.

18a. _____

18b. Denominator: For the reporting period, the total number of unduplicated clients who were inpatients of the inpatient units responding.

18b. _____

18c. Indicator: For the reporting period, the percentage of clients secluded at least once at the inpatient units responding.
(Numerator 18a. divided by denominator 18b.) **18c.** _____ %

19. Restraint Hours

19a. Numerator: For the reporting period, the total number of hours that all clients spent in restraint at the inpatient units responding. **19a.** _____

19b. Denominator: For the reporting period, the sum of the daily census (excluding clients on leave status) for each day (client days) multiplied by 24 hours for the inpatient units responding.
(Note: Same as 17b) **19b.** _____

19c. Indicator: For the reporting period, the hours of restraint as a percentage of client hours of the inpatient units responding.
(Numerator 19a. divided by denominator 19b.) **19c.** _____ %

20. Restraint of Clients

20a. Numerator: For the reporting period, the total number of clients (unduplicated) who were restrained at least once at the inpatient units responding. **20a.** _____

20b. Denominator: For the reporting period, the total number of unduplicated clients of the inpatient units responding.
(Note: Same as 18b) **20b.** _____

20c. Indicator: For the reporting period, the percentage of clients restrained at least once at the inpatient units responding.
(Numerator 20a. divided by denominator 20b.) **20c.** _____ %

21. Diversion from Criminal/Juvenile Justice Systems

21a. Numerator: The total number of mental health catchment or service areas responding that have jail diversion services. **21a.** _____

21b. Denominator: The total number of mental health catchment or service areas responding.
(Note: Same as 1b) **21b.** _____

21c. Indicator: The percentage of mental health catchment or service areas responding that have jail diversion services.
(Numerator 21a. divided by denominator 21b.) **21c.** _____ %

22. Integrated Substance Abuse and Mental Health Services

22a. Numerator: The total number of mental health catchment or service areas responding that have integrated substance abuse and mental health services. **22a.** _____

22b. Denominator: The total number of mental health catchment or service areas responding.

(Note: Same as 1b)

22b. _____

22c. Indicator: The percentage of mental health catchment or service areas responding that have integrated substance abuse and mental health services.

(Numerator 22a. divided by denominator 22b.)

22c. _____%

23. Trauma Service Provision

23a. Numerator: The total number of mental health catchment or service areas responding that have trauma services.

23a. _____

22b. Denominator: The total number of mental health catchment or service areas responding.

(Note: Same as 1b)

23b. _____

23c. Indicator: The percentage of mental health catchment or service areas responding that have trauma services.

(Numerator 23a. divided by denominator 23b.)

23c. _____%

ROSI Administrative-Data Profile: Mental Health Provider Characteristics

Provider Organization _____ Date _____

1. What is your organization's legal structure?

- a. Public
b. Private Nonprofit
c. Private for Profit
d. Other: _____

2. Geographic Location:

Country: _____

State/Province: _____

County: _____

3. Geographic Setting (check all that apply):

- a. Urban
b. Small City
c. Suburban
d. Rural
e. Remote/Frontier

4. How many consumers does your organization serve in mental health services each year (unduplicated)?

5. How many full time equivalents (FTEs) do you have on staff who directly provide mental health services at this time?

6. Which mental health services do you provide at this time? (Check all that apply.)

- a. Counseling/Psychotherapy
b. Case Management
c. Housing/Residential Services
d. Medication Management
e. Self-help/Consumer Run Service
f. Psychosocial Rehabilitation
g. Assertive Community Treatment (ACT)
h. Clubhouse
i. Alcohol/ Drug Abuse Treatment
j. Employment/Vocational Services
k. Other: _____

Thank You!

ROSI Administrative Data Profile – Mental Health Provider Level

Directions: Please respond to each item as thoroughly as possible. Please report data for your current activities or your most recently completed fiscal year. When the available data does not fully meet the specified item definition, please define the data used for that item on the form and continue to the next item. When data is not available, please indicate this on the form and continue to the next item.

1. Independent Peer/Consumer Operated Programs

- 1 Indicator: There is at least one independent peer/consumer operated program in our mental health catchment or service area.

Yes No

2. Peer/Consumer Delivered Service Funding

- 2a. Numerator: For the reporting period, the amount of program funds in our agency's mental health budget allocated for peer/consumer delivered services:

2a. _____

- 2b. Denominator: For the reporting period, the total amount of program funds in our agency's mental health budget:

2b. _____

- 2c. Indicator: For the reporting period, the percentage of our agency's program funds allocated for peer/consumer delivered services.

(Numerator 2a. divided by denominator 2b.)

2c. _____%

3. Medicaid Funded Peer/Consumer Delivered Services.

- 3a. Numerator: For the reporting period, the amount of Medicaid reimbursement our agency has received for services delivered in peer/consumer operated programs and by peer specialists.

3a. _____

- 3b. Denominator: For the reporting period, the total amount of Medicaid reimbursement our agency has received for behavioral health care.

3b. _____

- 3c. Indicator: For the reporting period, the percentage of Medicaid funding our agency has been reimbursed for peer/consumer delivered services.

(Numerator 3a. divided by denominator 3b.)

3c. _____%

4. Consumer Employment in Mental Health Systems

4. Indicator: The number of annual slots our agency specifically funded for training primary consumers in relevant educational and training programs and institutes to become mental health providers.

Number of Annual Slots

4. _____

5. Affirmative Action Hiring Policy

5. Indicator: Our agency has an affirmative action hiring policy regarding primary consumers.

Yes No

6. Advance Directives

6 Indicator: Our agency has an established mechanism to help clients develop advance directives.
 Yes No

7. Direct Care Staff to Client Ratio

7a. Numerator: For the reporting period, the total number of direct care staff (unduplicated) of our agency. **7a.** _____

7b. Denominator: For the reporting period, the total number of clients (unduplicated) served by our agency. **7b.** _____

7c. Indicator: For the reporting period, the ratio of direct care staff to clients for our agency. (Numerator 7a to denominator 7b.) **7c.** _____

8. State Recovery Oriented Mission Statement

8. Indicator: The state mental health authority’s mission statement explicitly includes a recovery orientation. (SKIP)

9. Local Agency Recovery Oriented Mission Statement

9 Indicator: Our agency has a mission statement that explicitly includes a recovery orientation.
 Yes No

If yes, please describe the initiatives for implementing this recovery orientation:

10. Consumer Involvement in Provider Contract Development

10a. Numerator: The number of our agency’s performance contracts with outside mental health service vendors that document primary consumer involvement in their development/yearly review. **10a.** _____

10b. Denominator: The total number of our agency’s performance contracts with outside mental health service vendors. **10b.** _____

10c. Indicator: The percentage of our agency’s performance contracts with outside mental health service vendors that have primary consumer involvement in their development/yearly review (i.e., specifying services, outcomes, target numbers, etc). (Numerator 10a. divided by denominator 10b.) **10c.** _____ %

11. State Office of Consumer Affairs

11 For the reporting period, the percentage of staff in the state office of consumer affairs who are primary disclosed consumers. (SKIP)

12. Regional/Local Office of Consumer Affairs

12. Indicator: Our regional mental health office or local mental health authority has an office of consumer affairs.

Yes No

13. Consumer Representation on State Planning Council

13. Indicator: For the reporting period, the percentage of state mental health authority planning council members who are disclosed primary consumers. (SKIP)

14. Consumer Representation on Local Boards

14a. Numerator: For the reporting period, the number of disclosed primary consumers (unduplicated) who serve on our agency’s board of directors.

14a. _____

14b. Denominator: For the reporting period, the total number of our agency’s board members (unduplicated).

14b. _____

14c. Indicator: For the reporting period, the percentage of our agency’s board membership that are disclosed primary consumers. (Numerator 14a. divided by denominator 14b.)

14c. _____ %

15. Involuntary Inpatient Commitments

15a. Numerator: For the reporting period, the number of involuntary inpatient admissions in our agency’s inpatient units.

15a. _____

15b. Denominator: For the reporting period, the total number of inpatient admissions in our agency’s inpatient units.

15b. _____

15c. Indicator: For the reporting period, the percentage of involuntary admissions in our agency’s inpatient units. (Numerator 15a. divided by denominator 15b.)

15c. _____ %

16. Involuntary Outpatient Commitments

16a. Numerator: For the reporting period, the number of our agency’s clients (unduplicated) on involuntary outpatient commitment status (new and continuing).

16a. _____

16b. Denominator: For the reporting period, the total number of our agency’s clients (unduplicated) who received outpatient services.

16b. _____

16c. Indicator: For the reporting period, the percentage of our agency's clients (unduplicated) under involuntary outpatient commitments.
(Numerator 16a. divided by denominator 16b.) **16c.** _____ %

17. Seclusion Hours

17a. Numerator: For the reporting period, the total number of hours that all of our agency's clients spent in seclusion at our agency's inpatient units.
17a. _____

17b. Denominator: For the reporting period, the sum of the daily census (excluding clients on leave status) of our agency's inpatient units for each day (client days) multiplied by 24 hours.
17b. _____

17c. Indicator: For the reporting period, the hours of seclusion as a percentage of client hours for our agency's inpatient units.
(Numerator 17a. divided by denominator 17b.) **17c.** _____ %

18. Seclusion of Clients

18a. Numerator: For the reporting period, the total number of clients (unduplicated) who were secluded at least once at our agency's inpatient units.
18a. _____

18b. Denominator: For the reporting period, the total number of unduplicated clients in our agency's inpatient units.
18b. _____

18c. Indicator: For the reporting period, the percentage of clients secluded at least once at our agency's inpatient units.
(Numerator 18a. divided by denominator 18b.) **18c.** _____ %

19. Restraint Hours

19a. Numerator: For the reporting period, the total number of hours that all clients of our agency's inpatient units spent in restraint.
19a. _____

19b. Denominator: For the reporting period, the sum of the daily census (excluding clients on leave status) of our agency's inpatient units for each day (client days) multiplied by 24 hours.
(Note: Same as 17b) **19b.** _____

19c. Indicator: For the reporting period, the hours of restraint as a percentage of client hours of our agency's inpatient units.
(Numerator 19a. divided by denominator 19b.) **19c.** _____ %

20. Restraint of Clients

20a. Numerator: For the reporting period, the total number of clients (unduplicated) who were restrained at least once at our agency's inpatient units.

20a. _____

20b. Denominator: For the reporting period, the total number of unduplicated clients of our agency's inpatient units.

(Note: Same as 18b)

20b. _____

20c. Indicator: For the reporting period, the percentage of clients restrained at least once at our agency's inpatient units.

(Numerator 20a. divided by denominator 20b.)

20c. _____ %

21. Diversion from Criminal/Juvenile Justice Systems

21. Indicator: Jail diversion services are available in our mental health catchment or service area for mental health consumers.

Yes No

22. Integrated Substance Abuse and Mental Health Services

22. Indicator: Integrated substance abuse and mental health services are available in our mental health catchment or service area for mental health consumers.

Yes No

23. Trauma Service Provision

23. Indicator: Trauma services are available in our mental health catchment or service area for mental health consumers.

Yes No

**Appendix K:
ROSI Pilot Information,
Guidelines and Process Form**

Appendix K: ROSI Pilot Information, Guidelines and Process Form

The Research Team makes the following requests of any person or agency that chooses to move forward on using the ROSI in the near future:

First, inform the Research Team of your wish to use the ROSI. This notification can be done by contacting the Research Team through either Steven Onken <so280@columbia.edu> or Jeanne Dumont <jdumont@lightlink.com>.

Second, use the measures as currently developed, do not shift the items around, change the wording of any of the items, or shorten the measures by only gathering data on a subset of items.

Third, design your use in such a way that the data could be shared with the Research Team. The local site would continue to 'own' the data, but would share the data set in a de-identified form with the Research Team. The Research Team's request will be subject to approval by the local site's research review, confidentiality and IRB processes as necessary.

Fourth, gather a small set of additional data that includes self-report survey respondent demographic variables, agency/authority-level descriptors, and methods of data collection.

By agreeing to these conditions, those using the ROSI measure will help advance recovery research in several ways. The data gathered will be added to the data from other pilot sites to: 1) improve the analysis of the statistical properties of the measure (psychometric testing); 2) improve the field's understanding of how program-/site-/systems-level variables influence findings; 3) build a data base on how differing sub-populations may differ in their responses to the ROSI; and 4) create a set of national norms that will help in setting benchmarks for improvements in programs and systems. The larger the data base that the Research Team can acquire, the better the chances of conducting a thorough and sound analysis.

GUIDELINES FOR THE ROSI

The ROSI is developed from and grounded in the lived experiences of adults with serious and prolonged psychiatric disorders. Thus, the ROSI consumer self-report survey and administrative profile are designed to assess the recovery orientation of community mental health systems for adults with serious and prolonged psychiatric disorders.

Using the 42-item ROSI consumer self-report survey without the allied use of the ROSI administrative profile is *not recommended*. The 42-item consumer self-report survey is complemented by the administrative data profile. Data that are generated by doing the self-report survey alone are incomplete. The administrative profile gathers data on important indicators of the recovery orientation of a system that are not covered on the consumer survey.

The ROSI consumer self-report survey currently does not have sub-scales and thus all 42 items should be administered.

It is important that you follow your process of human subject review in regards to securing approval for conducting the ROSI consumer self-report survey and for being in compliance with HIPAA regulations. As you determine the level of human subject review to complete, you will need to identify whether you need a written or verbal consent, what are the risks and benefits for participants, and what participant incentive, if any, you will provide.

You will need to develop a definition sheet for some of the terms used in the 42 items of the ROSI consumer self-report survey. In this sheet, you will explain or define for the participants what and whom you are asking them to evaluate. Thus, the definition sheets needs to be tailored to your specific mental health service delivery system. What do you mean when an item uses the term “program” (see item #21 for example). Do you mean programs operated by the local public mental health center or all local mental health programs regardless who operates them? Or are you limiting it to one program? A similar set of questions also applies to the term “staff” and how do you want to define “mental health services.” The clearer you are in your definition sheet, the easier it is for participants to complete the survey (and the easier for the survey administrator to answer participants’ questions).

When administering the ROSI consumer self-report survey, please point out to the participants that some of the items are negatively worded, for example, “Staff do not understand my experience as a person with mental health problems.” Please instruct the participants to read each item carefully in order to answer the negatively worded items accurately.

While the Research Team retained consumer’s phrasing in some individual items, as well as reduced the average reading level for the 42-item ROSI consumer self-report survey; some of the individual items require a high reading level. Some consumers may not have the literacy level needed to read or to understand some items. The Research Team strongly recommends that someone (such as a volunteer or peer specialist) be available to respondents during administration of the measure. This person can provide reading support and assistance, as well as answer questions. If the measure is administered by mail or internet, please provide such support through a toll free number.

The NY Office of Mental Health has translated the 42-item ROSI consumer self-report survey into Spanish. Because of differences in regional Spanish dialects and respondent literacy levels, the Research Team strongly recommends that an interpreter be available to Spanish speaking respondents during the administration of the survey. The 42-item ROSI consumer self-report survey is not available in other languages at this time, but the Research Team is open to working with interested parties in such efforts.

The Research Team is developing a set of definitions for the terms used in the 23 indicators of the ROSI administrative data profile. For example, we are defining what we mean by “Independent Peer/Consumer Operated Programs” in indicator #1. You will need to review these as some terms may need to be tailored to your specific mental health service delivery system. You must, however, document any deviations from the given definitions to be able to more accurately compare indicators over time or across systems.

It is very important that you record how you administered the ROSI using the ROSI Process Form, noting any variations that occurred (e.g., “x” number were completed in a group setting, “x” number were completed one-on-one, an English translator was available, etc.).

If you have questions, please contact the Research Team through either Steven Onken <so280@columbia.edu> or Jeanne Dumont <jdumont@lightlink.com>. Thank you!

