

**MENTAL HEALTH RECOVERY: WHAT HELPS AND WHAT HINDERS?
A NATIONAL RESEARCH PROJECT FOR THE DEVELOPMENT OF RECOVERY
FACILITATING SYSTEM PERFORMANCE INDICATORS**

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This national research project evolved from collaborative efforts among a team of consumer and non-consumer researchers, state mental health authorities, and a consortium of sponsors working to operationalize a set of mental health system performance indicators for facilitating mental health recovery. The project was conceptualized as a three phase process that involved grounded theory inquiry concerning the phenomenon of recovery, creation of prototype systems-level performance indicators, and large scale pilot testing.

Phase One has been completed. Structured focus groups and grounded theory qualitative research methods were used in nine states with a diverse cross-section of 115 consumer/survivors to gain knowledge on what helps and what hinders mental health recovery. The research team then used a process of qualitative coding and member checks to develop a single set of emergent themes and findings. These findings inform and articulate a conceptual paradigm for organizing and interpreting the phenomenon of recovery. While recovery is a deeply personal journey, there are many commonalities in people's experiences. Recovery is a product of complex, dynamic, synergistic and linked interaction among characteristics of the individual (the self, holism, hope, sense of meaning and purpose), characteristics of the environment (basic material resources, social relationships, meaningful activities, peer support, formal services, formal service staff), and the characteristics of the exchange (hope, choice, empowerment, independence, interdependence and referent power).

During Phase Two, the research team used the Phase One findings to develop two sets of performance indicators. One is based on consumer self-report data (survey format) and one is based on administrative data (administrative profile format). Both sets of indicators attempt to capture how mental health services help or hinder recovery. The consumer self-report indicator set underwent refinement using a Think Aloud process with 10 consumer/survivors. At this stage of development the consumer self-report indicator set involves 73 items divided between two response scales: frequency and agreement. Small scale prototype testing involving the eight state mental health authorities and approximately 200 consumer/survivors has taken place. Further review and reduction of the survey set is in process. The administrative profile set is also undergoing review involving all the participating state mental health authorities.

The final combined set of indicators will be incorporated into a long form, stand alone recovery orientation systems-level measure. The research team is also initiating efforts based on member check data and importance ratings collected during prototype testing to select a sub-set of the most critical indicators that will be incorporated into a short form recovery orientation measure for combination with existing performance indicator efforts, such as the MHSIP second generation performance indicator initiative, and other quality management initiatives.

What follows is the working set of indicators organized according self-report data and administrative data. The proposed indicators are further organized under the themes (and sub-themes) which emerged from Phase One findings. While there are self-report data items for each theme, administrative data indicators do not cover all the themes. (The findings guided decisions as to which approach better matched the concern or need being assessed.) The numbers corresponding to the self-report data are as they appear on the prototype survey.

CONSUMER SELF-REPORT PERFORMANCE INDICATOR ITEMS

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 assisted me in getting or keeping employment.
3. I have a chance to advance my education if I want to.
4. Mental health services assisted me in advancing my education if I wanted to.
21. I have opportunities 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 provided the assistance I needed in getting housing that I can afford.
7. I have reliable transportation when I need it.
8. Mental health services helped me get reliable transportation.
9. I have enough income to live on.
10. Mental health services provided the assistance I needed in obtaining enough income to live on.
11. I live in a safe location.
12. Mental health services helped me get housing in a safe location.
13. My medical benefits are inadequate (for example, no dental care, no eye care, no choice in doctors, limited prescriptions, etc.).
14. Mental health services helped me get adequate medical benefits.
22. Staff gave me information and stood up for me to get the benefits 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 provide full information in language I understand before I consent to treatment (including 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 respect and are responsive to my cultural background (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.
- 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 to develop 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. I have too 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 emotionally or physically harmed me.

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 and/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 viewed 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 to create a plan as to 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 I need to uphold my client and basic human rights.

ADMINISTRATIVE DATA PERFORMANCE INDICATOR ITEMS

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

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 number of direct care staff (unduplicated) who are disclosed consumers (former or current) during the reporting period.

Denominator: The total number of direct care staff (unduplicated) during the reporting period.

Measure 2: There are programs/institutes specifically designed to train consumers to become mental health providers. (Yes/No)

Performance Indicator: Peer-Operated Services Funding

Measure 1: The percent of state program funds allocated for peer-operated services.

Numerator: The amount of program funds in the state mental health budget allocated for peer-operated services during the reporting period.

Denominator: The total amount of program funds in state mental health budget during the reporting period.

Measure 2: The percentage 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.

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).

Performance Indicator: Advance Directives

Measure 1: The percent of local mental health provider agencies that have a mechanism to help clients develop advance directives.

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

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

Measure 2: The percent of local mental health provider agencies that have a process for ensuring that advanced directives are followed.

Numerator: The number of local mental health provider agencies that have a process for ensuring that advanced directives are followed.

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

Performance Indicator: Involuntary Inpatient Commitments

Measure: The percent of clients under involuntary inpatient commitments.

Numerator: The number of clients who received involuntary inpatient commitments during the reporting period.

Denominator: The total number of clients who received inpatient services during the reporting period.

Performance Indicator: Involuntary Outpatient Commitments

Measure: The percent of clients under involuntary outpatient commitments.

Numerator: The number of clients who received involuntary outpatient commitments during the reporting period.

Denominator: The total number of clients who received outpatient services during the reporting period.

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).

MHSIP's Proposed Indicator on Cultural Competence

Add Measure: The proportion of direct care staff race/ethnicity demographic to client race/ethnicity demographic within each local mental health provider agency.

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 number of direct care staff (unduplicated) during the reporting period.

Denominator: The total number of clients (unduplicated) during the reporting period.

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).

MHSIP's Proposed Indicator on Percent of Persons Receiving Services in the Least Restrictive Service Setting

Add Measure: The percent of contacts made by mental health agency staff to clients that occurred outside of the office.

Numerator: Total number of contacts made by mental health agency to clients that occurred outside of the office during the reporting period.

Denominator: Total number of contacts by the mental health agency to clients during the reporting period.

Performance Indicator: Recovery Oriented Mission Statement

Measure 1: The state mental health authority's mission statement includes a recovery orientation. (Yes/No).

Measure 2: The percent of local mental health provider agencies whose mission statements include a recovery orientation.

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

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

Performance Indicator: Consumer Specified Outcomes

Measure: The percent of agency performance contracts that have consumer specified outcomes.

Numerator: The number of service contracts documenting consumer involvement in, and specification of service contract outcomes.

Denominator: The total number of service contracts.

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 number State Office of Consumer Affairs staff (unduplicated) who are disclosed consumers (former or current) during the reporting period.

Denominator: The total number of State Office of Consumer Affairs staff (unduplicated) during the reporting period.

Measure 2: The percent of regional mental health offices/local mental health authorities (or equivalent) that have an Office of Consumer Affairs.

Numerator: The number 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 number of regional mental health offices/local mental health authorities (or equivalent) during the reporting period.

Measure 3: The proportion of central office administrative budget allocated to the State Office of Consumer Affairs.

Numerator: The amount of funds in 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.

Performance Indicator: Consumer Inclusion in Governance and Policy

Measure 1: The percent of state mental health authority planning council members that are primary consumers.

Numerator: The number of primary consumers (unduplicated) who are state planning council members during the reporting period.

Denominator: The total number state planning council members (unduplicated) during the reporting period.

Measure 2: The percent of local mental health provider agencies that mandate participation of primary consumers on their governing boards.

Numerator: The number of local mental health provider agencies that mandate participation of primary consumers on their governing boards.

Denominator: The total number local mental health provider agencies with governing boards.

Measure 3: The percent of local mental health provider agency board membership that are primary consumers.

Numerator: The number of primary consumers (unduplicated) who serve on local mental health provider agency boards during the reporting period.

Denominator: The total number local mental health provider agency board members (unduplicated) during the reporting period.

Measure 4: The state mental health authority directly involves primary consumers with policy development and review.

Numerator: The number of polices in the denominator (unduplicated) reviewed by primary consumers prior to the public comment period.

Denominator: The total number of new polices and current policies with proposed revision (unduplicated) released for public comment during the reporting period.

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

MHSIP's Proposed Indicators on Seclusion

Existing Measure: The percent of clients and client service hours regarding the use of seclusion.

MHSIP's Proposed Indicators on Restraints

Existing Measure: The percent of clients and client service hours regarding the use of restraints.

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

MHSIP's Proposed Indicator on Medication Errors

Add Measure: The percent of clients whose total dosage of medication exceeds established clinical parameters.

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).

MHSIP's Proposed Indicator on Involvement in the Criminal Justice/Juvenile Justice System

Add Measure: The percent of mental health catchment or service areas that have jail diversion services.

Numerator: Total number of mental health catchment or service areas that have jail diversion services.

Denominator: Total number of mental health catchment or service areas.

MHSIP's Proposed Indicator on Reduced Substance Abuse Impairment

Add Measure: The percent of mental health catchment or service areas that have integrated substance abuse and mental health services.

Numerator: Total number of mental health catchment or service areas that have integrated substance abuse and mental health services.

Denominator: Total number of mental health catchment or service areas.

Performance Indicator: Trauma Service Provision

Measure: The percent of persons with severe mental illness receiving trauma services.

Numerator: The number of persons with severe mental illness receiving trauma services (unduplicated) during the reporting period.

Denominator: The total of persons served in the community, 18 and older, with any serious mental illness (unduplicated) during the reporting period.

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

Performance Indicator: General Public Education and Awareness Campaigns

Measure: The proportion of state budget funds earmarked for public awareness education, prevention, and/or wellness campaigns.

Numerator: The amount of funds in the state mental health/behavioral health budget allocated for public awareness education, prevention, and/or wellness campaigns during the reporting period.

Denominator: The total amount of funds in the state mental health/behavioral health budget during the reporting period.