

DRAFT FOR REVIEW

THE MHSIP CONSUMER SURVEY

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Prepared by: Vijay Ganju
Director
Planning, Research & Evaluation
Texas Department of MHMR

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THE MHSIP CONSUMER SURVEY

INTRODUCTION

The MHSIP consumer survey was developed and proposed as one of several instruments to measure the domains, concerns and indicators of the MHSIP Consumer-Oriented Report Card, which was published in April 1996. Since then, several states have implemented components of the report card and many of these efforts have included this consumer survey. As a result of these experiences, modifications have been made to the original survey, psychometric properties have been tested, consumers in several settings have reacted to the relevance of the items and there is now a better understanding of (1) how to administer the survey, (2) the factor structure of the survey items and (3) scoring methodologies.

This document provides a brief overview of the history, development, revisions, applications and commonly-asked questions about the MHSIP Consumer Survey. It also presents a revised version, an abbreviated version, and describes current efforts to refine and develop the instrument.

HISTORY

To understand the purpose of the MHSIP Consumer Survey, it is important to understand its origins and some of the thinking that went into the development of the report card. A task force appointed by the Mental Health Statistics Improvement Program (MHSIP) Advisory Group (supported by the Center for Mental Health Services (CMHS) in the Substance Abuse and Mental Health Services Administration (SAMHSA)) consisting of consumers, family members, researchers and federal, state and local mental health agency representatives developed the MHSIP Consumer-Oriented Report Card.

The task force identified and prioritized concerns related to the domains of ACCESS, QUALITY/APPROPRIATENESS, OUTCOMES, and PREVENTION. It considered the domain of SATISFACTION and decided that general satisfaction was not important from a consumer perspective. The more critical aspect was the consumer perception and experience of ACCESS, QUALITY/APPROPRIATENESS AND OUTCOMES. The underlying concept was that if the report card was attempting to evaluate the performance of a mental health system, one way to find out was to ask the consumer. While the report card included objective measures based on administrative and cost data and on clinical instruments, the MHSIP

Consumer Survey was designed to obtain the subjective evaluation of the consumer. Specifically, the MHSIP Consumer Survey was designed with 40 items related to the Access, Quality/Appropriateness and Outcomes domains that reflected concerns that were important to consumers.

At the same time, specific concerns were identified with each domain. For example, a priority concern identified related to ACCESS was that “Entry into mental health services is quick, easy and convenient”.

Three indicators were associated with this concern:

- The average length of time from request for services to the first face-to-face meeting with a mental health professional
- The percentage for whom the location of services is convenient
- The percentage of consumers for whom appointment times are convenient

The first indicator had a performance measure which used data from enrollment/encounter data. But the second and third indicators were operationalized by using specific items from the MHSIP Consumer Survey. The specific item for the second indicator was:

The location of services was convenient (parking, public transportation, distance, etc.)

And for the third indicator was:

Services were available at times that were good for me.

This dual use of the items in the survey has been a source of confusion. The survey was originally designed in a general way to tap the broad domains using key concerns and items culled from consumer surveys reviewed. Then, as the indicators were operationalized, some of the measures used the MHSIP Consumer Survey as a source. Even at the time of design of the survey, there was concern that a one-or-two item scale might not be reliable. But task force members agreed that it was important to reflect that there was some measure related to the concern.

So there were general items related to the key domains. Some of these were related to specific concerns; some were not. This explains why there are some items in the survey which do not have a corresponding concern.

Also, as the survey was being designed, while satisfaction was not considered important, a few broadly used satisfaction items were included, more to understand the relationship between the other items and the more generally used satisfaction items than because it was a domain that needed to be measured.

To summarize, the primary purpose of the MHSIP Consumer Survey was to measure consumer perception of care related to Access, Quality/Appropriateness and Outcomes.

An important aspect of the survey, and this was a point that was repeatedly emphasized by consumers, was an attempt to measure both positive and negative outcomes and experiences. This resulted in items such as “I experienced harmful medication side effects” and “I was unable to get the services I thought I needed” and “Staff were not sensitive to my cultural/ethnic background”.

In initial tests conducted by Dr. Shula Minsky, the negatively worded items proved problematic. But, to have items that related to “dissatisfaction,” they were retained in the survey.

DEVELOPMENT

After the report of the task force on the MHSIP Consumer-Oriented Report Card was released in April 1996, the Center for Mental Health Services initiated a grant program to support the development of state-level mental health performance measurement systems and implementation of the MHSIP report card.

As part of this initiative, several states implemented the consumer survey. In some states, after pilot tests were conducted, items were revised and re-worded. Consistently, states implementing the survey found that the negatively-worded items, especially some with double negatives, were confusing. Several states with this similar experience worked together and jointly re-worded the negative items. (For particular items, some states used two revised versions of the same item.)

Individual states then implemented the survey. The methods of administration varied: in some states, mail surveys were used; in others, face-to-face interviews were conducted by consumers. The states then proceeded to analyze the data, the instrument’s psychometric properties, and produce reports based on the surveys conducted. Since specific scoring methodologies were not developed, states developed their own

scoring procedures. Some states developed translations in Spanish and Vietnamese. A few states also developed family member versions.

Recognizing the urgent need for standardization of performance measures across state systems, the Center for Mental Health Services initiated a five-state feasibility study to understand issues related to standardized reporting. As part of this initiative, which was coordinated by the NASMHPD Research Institute, states that had experience with the MHSIP Consumer Survey were convened to review results and experiences with the objective of developing guidelines and standardized procedures. Data from several states were pooled and then analyzed by Dr. Jack Wackwitz. This analysis confirmed the factor structure (ACCESS, QUALITY/APPROPRIATENESS, OUTCOMES, SATISFACTION), demonstrated that the survey had strong psychometric properties and that a sub-set of 21 items could account for the variance of the 40 items. An issue, however, was that some of the items that were redundant from a statistical viewpoint reflected concerns that had been identified as important by consumers.

Next Chapter. the National Committee on Quality Assurance (NCQA) created a Behavioral Health Measurement Advisory Panel (MAP) to develop better measures related to behavioral health. In discussions about which instruments could be used, the MHSIP Survey was reviewed and was endorsed for pilot testing. The objective here is to use this as a standardized instrument for behavioral health managed care, both for persons with serious mental illness and persons with mental illness of a more episodic nature. Two members of the Behavioral Health MAP – Vijay Ganju and Tom Trabin - worked with Jack Wackwitz to develop a 21-item instrument that could be used in managed care settings. (The wording was also modified to reflect differences between provider and managed care settings.)

Another instrument – the Consumer Assessment of Behavioral Health Services (CABHS), which was being developed by AHCPR – was also under consideration by NCQA. Both instruments are being tested through the Human Services Research Institute (HSRI) so that one of the instruments – or some combination – can be recommended for use by NCQA. Results are expected in 1999.

REVISED VERSIONS

As a result of the rewording of the negative items for the NCQA versions of the MHSIP survey, a new version of the original 40-item consumer survey was developed. This is attached.

Also, the long and short versions submitted to NCQA – with specific wording for managed care settings – are included. The 21-item version is intended for general use; the 40-item version is recommended primarily for respondents who have a serious mental illness.

And finally, the 21-item version, which corresponds to the revised 40-item non-managed care version, is also attached.

APPLICATION

The population with which the survey has most commonly been used is adults with serious mental illnesses in community settings. Some states have used the survey successfully with adults with episodic mental illnesses and adults with a history of substance abuse.

As mentioned above, the survey has been administered through a mail survey, by consumer interviews and through a phone survey. In Texas, the response rate to a mail survey (no follow-up) conducted with a random sample of adults with mental illness who were receiving or had received services in the community was 41 percent (statewide). Currently, a study in Texas is comparing three different administration strategies: mail surveys, consumers interviewing consumers, and phone surveys.

With some modifications, the survey has also been used in hospital and residential treatment settings. A standardized inpatient version is currently under development.

COMMONLY-ASKED QUESTIONS

How do you score the survey?

To develop a score for an item, compute the percentage of respondents that “strongly agree” or “agree”. To develop a score for the domain, compute the average percentage for the items in that domain.

(Similarly, percentages can be computed for respondents that “strongly disagree” or “disagree”.)

Does the survey work for children and adolescents?

The items are oriented more towards adults. The survey does not work well for children and adolescents.

Has the survey been used in state hospital settings?

Not commonly. A modified version has been developed in some states in which some items have been removed (e.g. “My calls were returned within 24 hours.”) A modified version has also been used in residential treatment settings.

Do translations of the survey exist?

Several states have developed translations in Spanish (Rhode Island, Texas, New Mexico, Colorado). Vietnamese versions also have been used (Rhode Island).

Is there a family version?

Some states have developed a family version. An issue regarding implementation is whether a consumer wants the family member to receive and respond to the survey. Also, establishing contact with a family member can prove logistically difficult. Prior consent of the consumer is required.

Does the survey work for persons with substance abuse problems?

Some states have used the survey with single-diagnosis substance abuse consumers without encountering major problems. One or two items do not work well with this population.

Should we use the 21-item version or the 40-item version?

If the report will produce a score for each domain, then the 21-item version is as effective as the 40-item version. If there is interest in responses to specific items that reflect particular concerns, the 40-item version should be used. A general rule-of-thumb is to use the 40-item version if the population primarily consists of persons with serious mental illness. (The length of the instrument has not posed a problem in any of the states in which it has been used. Also response rates are comparable, if not better than those for other surveys.)

Is the MHSIP Consumer Survey used as a pre-post measure?

In general, the MHSIP consumer survey has been used to measure the aggregated response of consumers at one point in time. That is, the survey has been used to measure items or domains for a group of consumers rather than to track changes for an individual consumer.

MHSIP TASK FORCE ON MENTAL HEALTH REPORT CARD

Consumer Survey (Full Version)

Please indicate your agreement/disagreement with each statement by circling what best represents your opinion.

1. I liked the services that I received.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
2. If I had other choices, I would still choose to get services from this health plan.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
3. I would recommend this health plan to a friend or family member.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
4. I was able to get the services I wanted even though I could not pay for them.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
5. The location of services was convenient (parking, public transportation, distance, etc.).	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
6. My caregivers were willing to help as often as I felt it was necessary.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
7. My calls were returned within 24 hours.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
8. Services were available at times that were good for me.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
9. I was able to get all the services I thought I needed.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
10. I was able to see a psychiatrist when I wanted to.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
11. My caregivers believed that I could grow, change and recover.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
12. I felt comfortable asking questions about my treatment and medication.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
13. I felt free to complain.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
14. My caregivers and other staff respected my rights.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
15. I was given information about my rights.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
16. I was encouraged to take responsibility for how I live my life.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
17. I was told what side effects to watch for.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
18. My wishes about who is and is not to be given information about my treatment were respected.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
19. I, not staff, decided my treatment goals.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
20. Staff were sensitive to my cultural/ethnic background.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable

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**MHSIP TASK FORCE ON MENTAL HEALTH REPORT CARD
Consumer Survey (Full Version)**

Please indicate your agreement/disagreement with each statement by circling what best represents your opinion.

21. My caregivers helped me obtain the information I needed so that I could take charge of managing my illness.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
22. My caregivers behaved as if I could choose what is best for me.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
23. I was encouraged to use consumer-run programs (support groups, drop-in centers, crisis phone line, etc.).	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
24. Some of the services I received were not helpful.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
25. My caregivers were competent and knowledgeable.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
<u>AS A DIRECT RESULT OF SERVICES I RECEIVED</u>						
26. I deal more effectively with daily problems.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
27. I feel better about myself.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
28. I am better able to control my life.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
29. I experienced harmful medication side effects.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
30. I am better able to deal with crisis.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
31. I am getting along better with my family.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
32. I do better in social situations.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
33. I do better in school and/or work.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
34. I do better with my leisure time.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
35. My housing situation has improved.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
36. My symptoms are not bothering me as much.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
37. I have become more independent.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
38. The medications I am taking help me control symptoms that used to bother me.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
39. I have become more effective in getting what I need.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
40. I can deal better with people and situations that used to be a problem for me.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable

MHSIP Consumer Survey (Short Version)

Please indicate your agreement/disagreement with each statement by circling what best represents your opinion.

1.	I liked the services that I received.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
2.	If I had other choices, I would still choose to get services from this health plan.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
3.	I would recommend this health plan to a friend or family member.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
4.	The location of services was convenient (parking, public transportation, distance, etc.).	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
5.	My caregivers were willing to help as often as I felt it was necessary.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
6.	My calls were returned within 24 hours.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
7.	Services were available at times that were good for me.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
8.	I was able to get all the services I thought I needed.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
9.	My caregivers believed that I could grow, change and recover.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
10.	I felt free to complain.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
11.	I was told what side effects to watch for.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
12.	My wishes about who is and is not to be given information about my treatment were respected.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
13.	My caregivers were sensitive to my cultural/ethnic background.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
14.	My caregivers helped me obtain the information needed so I could take charge of managing my illness.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
As a Direct Result of the Services I Received:							
15.	I deal more effectively with daily problems.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
16.	I am better able to control my life.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
17.	I am better able to deal with crisis.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
18.	I am getting along better with my family.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
19.	I do better in social situations.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
20.	I do better in school and/or work.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
21.	My symptoms are not bothering me as much.	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable

MHSIP TASK FORCE ON MENTAL HEALTH REPORT CARD
Consumer Survey

In order to improve mental health services to people like you, we need to know what you think about the treatment you received, the people who provided it, and the results of this treatment.

Please indicate your agreement/disagreement with each of the following statements by circling the number that best represents your opinion. If the question is about something you have not experienced, circle the number 9, to indicate that this item is "not applicable" to you.

	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
1. I like the services that I received here.	1	2	3	4	5	9
2. If I had other choices, I would still choose to get services from this agency.	1	2	3	4	5	9
3. I would recommend this agency to a friend or family member.	1	2	3	4	5	9
4. I was able to get the services I wanted even if I could not pay for them.	1	2	3	4	5	9
5. The location of services was convenient (parking, public transportation, distance, etc.).	1	2	3	4	5	9
6. Staff were willing to see me as often as I felt it was necessary.	1	2	3	4	5	9
7. Staff returned my call within 24 hours.	1	2	3	4	5	9
8. Services were available at times that were good for me.	1	2	3	4	5	9
9. I was able to get all the services I thought I needed.	1	2	3	4	5	9
10. I was able to see a psychiatrist when I wanted to.	1	2	3	4	5	9
11. Staff here believe that I can grow, change, and recover.	1	2	3	4	5	9
12. I felt comfortable asking questions about my treatment and medication.	1	2	3	4	5	9
13. I felt free to complain.	1	2	3	4	5	9
14. Staff respected my rights.	1	2	3	4	5	9
15. I was given information about my rights.	1	2	3	4	5	9
16. Staff encouraged me to take responsibility for how I live my life.	1	2	3	4	5	9
17. Staff told me what side effects to watch for.	1	2	3	4	5	9
18. Staff respected my wishes about who is, and is not, to be given information about my treatment.	1	2	3	4	5	9
19. I, not staff, decided my treatment goals.	1	2	3	4	5	9

MHSIP TASK FORCE ON MENTAL HEALTH REPORT CARD
Consumer Survey

In order to improve mental health services to people like you, we need to know what you think about the treatment you received, the people who provided it, and the results of this treatment.

Please indicate your agreement/disagreement with each of the following statements by circling the number that best represents your opinion. If the question is about something you have not experienced, circle the number 9, to indicate that this item is “not applicable” to you.

	Strongly Agree	Agree	I am Neutral	Disagree	Strongly Disagree	Not Applicable
20. Staff were sensitive to my cultural/ethnic background (race, language, religion, etc.).	1	2	3	4	5	9
21. Staff helped me obtain the information I needed so that I could take charge of managing my illness.	1	2	3	4	5	9
22. Staff believe that I can choose what is best for me.	1	2	3	4	5	9
23. I was encouraged to use consumer-run programs (support groups, drop-in centers, crisis phone line, etc.).	1	2	3	4	5	9
24. All of the services I received were helpful.....	1	2	3	4	5	9
25. Staff I worked with were competent and knowledgeable.	1	2	3	4	5	9
AS A DIRECT RESULT OF SERVICES I RECEIVED:						
26. I deal more effectively with daily problems.	1	2	3	4	5	9
27. I feel better about myself.	1	2	3	4	5	9
28. I am better able to control my life.	1	2	3	4	5	9
29. I experienced harmful medication side effects.	1	2	3	4	5	9
30. I am better able to deal with crisis.	1	2	3	4	5	9
31. I am getting along better with my family.	1	2	3	4	5	9
32. I do better in social situations.	1	2	3	4	5	9
33. I do better in school and/or work.	1	2	3	4	5	9
34. I do better with my leisure time.	1	2	3	4	5	9
35. My housing situation has improved.	1	2	3	4	5	9
36. My symptoms are not bothering me as much.	1	2	3	4	5	9
37. I have become more independent.	1	2	3	4	5	9
38. The medications I am taking help me control symptoms that used to bother me.	1	2	3	4	5	9
39. I have become more effective in getting what I need.	1	2	3	4	5	9
40. I can deal better with people and situations that used to be a problem for me.	1	2	3	4	5	9