

Nothing About Us, Without Us:
Involvement of the Consumer Voice in
Minnesota's performance Indicator Process

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Performance Indicator Process

- Adult MH Initiatives
Focus- Those at risk of hospitalization
- Regional Meetings with Consumers & other stakeholders
- Statewide Group of Consumers and other stakeholders from regions
- Process involved education about performance indicators.
- Reviewed MHSIP, 5 state feasibility study, NASMHPD proposed indicators & own suggestions

Recommended Performance Indicators in Minnesota

1) Reduction in institutional days (RTCs/SHs) / Improve Community Tenure

2) % of persons readmitted to psychiatric inpatient care within 30 and 160 days of discharge

3) % of adults with SPMI population for whom there are positive changes in living situation.

4) % of adults with SPMI with an increase in meaningful productive activity, including employment to meet their income and health care needs as well as skill and interests.

5) % of adults with SPMI for whom there are positive changes in level of functioning (Incl.- social contacts)

6) % of adults with SPMI who are linked to physical health services

7) % of adults with SPMI receiving services who rate access to care positively

8) Effective & Responsive Treatment Plans:

% of persons with SPMI who are actively involved in decisions regarding their own treatment

State Advisory Work Group Recommendations

- 1) Use existing data sources whenever possible.
- 2) Expand the indicators to all adults with serious mental illness in the public mental health system.
- 3) Establish an easy to follow sampling procedure to collect the information that is not already available.
- 4) Use consistent forms or questions across the system.
- 5) Provide timely feedback to consumers and stakeholders.
- 6) Recommend changes to the Adult Consumer Information Form related to living situation & employment to fit with performance indicator.
- 7) Recommend greater use of consumers in administering some of the consumer surveys.

Consumer Survey Issues

- Preference for grading scale (A - F) instead of Agree - Disagree
- The “Process” of the survey can be much more meaningful using consumer surveyors.
- Using a consumer organization provides “empowerment”.
- What is being rated by the survey? Is it a particular provider, service or the “MH System”? Must be clear about it.

Some Lessons Learned (or remembered)

- Consumers “Live” the system & know it very well
- Remember the original target audience of a MH report card were consumers.
- Consumers should be paid for their time & expenses when attending meetings.
- There are many consumer views, make sure enough are heard in the process.

Wendy Rea's Presentation

I. Background:

A. Consumer - Since 1988

B. Why I wanted to be involved, as a representative of consumers, in the process of improving the MH system.

C. Education - BA in American Studies from St. Cloud State , Nov. 1996

Relevancy of: Made me aware of the importance of the consumer voice to direct change and empower themselves as a subculture within our society.

D.. Involvement as a representative of Consumers:

1. Initiative: Began involvement in Jan. 1997

2. CSN: Started as a volunteer in March 1997

Became staff March 1998

3. Performance Indicators: Nov. of 1997

II. Performance Indicator Process:

A. Performance Indicator Grant activities over 2 year grant period from Nov. 1997 - Nov. 1999.

1. Reviewed Initiative data statewide.
2. Developed a set of statewide performance indicators.
3. Identified forms of data collection appropriate to each indicator.
 - A. Some Indicators could be measured through already existing data collection.
 - B. Others could not; statewide consumer satisfaction data did not exist for most services, but was being done on a volunteer basis among Initiatives consumers. However, return on this survey was lower than had been hoped for.
4. Developed an alternative for consumer satisfaction data collection:
 - A. Consumer to consumer survey
 - B. To be administered by CSN: who had recently implemented a successful housing survey on a statewide basis.

B. Performance Indicator Implementation Phase: 2000 & 2001

1. DHS staff has implemented statewide efforts to gain provider support of the Chosen Indicators, and has maintained consumer participation in this phase.
2. DHS provided funding for development and implementation of consumer survey.

A. Collaboration occurred between DHS and a representative for CSN to develop the survey.

B. Oct. 2000: CSN hired and trained consumers to do The survey.

a. # hired

b. Team Leader vs Team Surveyor

C. Dec. 2000: DHS sent out a letter of support to providers asking them to work with CSN to get a random sampling of consumers.

D. Jan. 2001: Collection of data began and will continue until October.

a. Work with provider to set up sites and times. Provider contacts consumers personally or by mail.

b. Team members go to site: our area does them one on one, others do them in groups.

c. Team leader collects surveys and sends to Erica, who then sends them onto DHS.

E. Current status of Data collected.

III. Conclusion: Throughout my experience with my local Initiative, CSN and the Performance Indicator Process, I have witnessed the efforts by DHS to empower consumers.

A. On a systems level:

1. By including consumer involvement as a requirement to receive M.H. Pilot/Initiative funds.
2. By giving consumers an equal voice with providers in the development and selection of performance indicators.
3. DHS has secured resources for CSN to conduct the survey.

B. On a personal level:

1. I have experienced feedback from individuals from the MDHS staff that indicates they were listening and understanding when I spoke.
2. Their support of CSN has improved the quality of my life and other consumers due to opportunities for involvement and employment based on our consumer status.

**Preliminary Results of Minnesota Consumer Survivor Network Survey
For 504 Surveys of CSP or Day Treatment Consumers Through April 2001
Survey was Adopted from Louisiana C'est Bon Version of MHSIP Survey**

	Failing or Poor	OK	Very Good or Excellent
	%	%	%
The location of the services (distance, transportation, parking) accessible?	6%	21%	72%
Getting your phone calls returned promptly?	10%	28%	62%
Getting services at times that were good for you?	7%	23%	70%
Seeing a psychiatrist when you need to?	13%	19%	68%
The staff respecting you as a person?	7%	16%	77%
Providers being open to questions about your treatment and medications?	6%	21%	73%
Providers giving you a choice about what is best for you?	11%	21%	68%
Providers helping you obtain the information you need to manage your illness?	11%	22%	67%
Providers encouraging you to use consumer-run programs (support groups, drop-in centers, Warm Lines)?	10%	17%	72%
Providers involving you in deciding your treatment goals?	10%	22%	68%
Providers' sensitivity to your cultural background (race, religion, or language)?	7%	18%	75%

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	Failing or Poor	OK	Very Good or Excellent
	%	%	%
Cope with a crisis?	16%	28%	56%
Feel better about yourself?	11%	31%	57%
Get along better with your family?	15%	29%	56%
Do better in being able to work or go to school?	20%	31%	50%
Do better with social situations?	11%	33%	55%
Improve your housing situation?	12%	30%	58%
Become more independent?	10%	29%	61%
Deal with situations that used to be a problem for you?	12%	31%	57%
How would you grade how well the doctor has responded to any medication side effects?	11%	17%	72%
How would you grade how well the medications have helped control symptoms	8%	23%	68%