Grading the States

A Report on America's Health Care System for Serious Mental Illness

2006

NAMI: The National Alliance on Mental Illness

Consumer and Family Test Drive Methodology and Results

Purpose

An effective mental health system has to be both inclusive and responsive. The Consumer and Family Test Drive (CFTD) was designed to measure actual experiences of consumers and families as they attempted to navigate the system. Specifically, the CFTD sought to determine the level of ease a consumer and/or family member would experience when seeking information about mental health through a state mental health authority's website and/or phone service.

To conduct this study, NAMI National contracted with NAMI New Hampshire to develop and conduct a brief survey to be included in the National State Report Card project. CFTD results represent 10 percent of each state's overall grade in NAMI's *Grading the States* report.

Survey

The survey included 10 common questions and concerns pertaining to mental health issues, rated on a Likert scale of 0-4:

- 0 represented "no information found"
- 1 represented information that was found "with great difficulty"
- 2 represented information that was found "with some difficulty"
- 3 represented information that was found "easily"
- 4 represented information that was found "very easily"

The maximum total score per survey was 40 points. A copy of the survey instrument. A copy of the survey is attached.

The goal was to have two family members and two consumers survey each state. For a state, each rater would conduct both a phone and web survey, for a total of eight surveys per state.

Raters

Consumers and family members were recruited from NAMI New Hampshire's network of volunteers and leadership. All those recruited were currently receiving services, or have received services from the New Hampshire community mental health system. In the end, six consumers and five family members were recruited to be raters. All family members were asked to survey 20 states each. Four consumers were asked to survey 20 states each, and 2 were asked to survey 10 each. Raters received a stipend when their completed surveys were received, and they were also reimbursed for postage and phone bills.

Inter-rater Training

In order to ensure inter-rater reliability, two one-hour orientation sessions were held and raters were asked to attend one of these two sessions. Raters were all trained under the same set of directions. They were to treat their information-gathering role as if they were new to a state and/or were participating in a NAMI survey, and wanted information about where to go for treatment and what services were available.

Training also attended to issues like: How to search for a state mental health authority's website, when to consult the provided "cheat sheet" (NAMI National provided phone and website information if the consumer and/or family member could not find it on their own); how long to spend on each item before checking the "No info found" box; inclusion of anecdotal information; how to score the fact that multiple voice messages were left (score of 0); when to "give up" searching for information and provide a score.

Data Collection

The data collection period ran 6 weeks, from the beginning of November to mid-December, 2005. Before raters began their surveys, project staff piloted the survey on a few states to determine possible problems that raters might encounter during the process. Throughout the data collection period, project staff provided extensive and consistent phone technical assistance to raters.

In all, 322 surveys were collected out of a possible 400. Reasons for not obtaining the full 400 surveys included: a family member dropped out of the project for personal reasons; raters were sidetracked by the holidays and work responsibilities; in one phone case, the rater had a negative experience with a state mental health authority staff member and, as a result, did not wish to make any more phone calls.

All state surveys had consumer and family member representation. Although the goal was to have eight surveys completed for each state, final completed state survey data points ranged from 4-8. In the case where states only had four completed surveys, these represented data from at least one family member and one consumer, and included at least two phone surveys and two website surveys.

Scoring

A state's CFTD score represented 10% or 10 points of its overall grade. The CFTD rating system was established as such: For each state, a Mean Score was obtained by calculating the average total survey score (out of a possible 40 points) for that state. The Mean Score was calculated using all completed phone and website surveys for that state. States were then rank ordered according to their Mean Score, and distributed into 10 groups of 5 states each. Final scores were curved as follows: the top 5 states received 10 points for their CFTD score, the next 5 received 9 points for their CFTD score, and so on. In one case, a sixth state was placed in a group because of a tied score.

Results and Discussion

Overall, the results point to major lags in the communication of important service and treatment information. Given the overall fragmentation of mental health systems, this is not surprising, but is not acceptable.

Clear trends emerged across states and across communication medium:

- **Inadequate phone and website accessibility**

Over 80 percent of states did not acquire even *half* of the total possible points on the survey, indicating that the vast majority of state mental health authorities do not adequately communicate basic information to their customers. Both consumers and family members felt frustrated and discouraged at the difficulty in accessing information, feelings that are potential roadblocks to empowering consumers and families to play an active role in their treatment. Greater emphasis should be placed on enhancing state information service systems. Making contact with public health service systems easy and informative for consumers and family members will add to the likelihood of better treatment outcomes.

- **Information systems lack cultural competency**

As indicated above, accessibility to information on mental health is inadequate for the majority population, but it is even worse for diverse, underserved populations. In the CFTD, raters assessed the ease of access to information on mental illnesses and their treatment *in a non-English language*, using a broad definition of "non-English speaker" that included those who are deaf and hard of hearing, as well as those who are blind.

The mean for this item, including both phone and website surveys, was the lowest of any item (1.19 points out of 4 possible points). Such a low score indicates that information in a non-English language was found *only with great difficulty*. Some states did better than others on this item, specifically New York, California, Arizona and Maryland, although no state earned a perfect score. Disappointingly, some states with large multicultural populations scored well below the mean, including Virginia, New Mexico and Florida.

It is well documented that individuals of multicultural backgrounds already face a myriad of barriers in accessing services, and the experience of this survey just confirms that sad reality.

• Phone services are superior to websites
The mean scores for phone service were significantly greater than the scores for web service. On average, states scored 17.02 points on their phone surveys, and 12.99 points on their website surveys. Some states (Massachusetts and Texas) had much higher mean scores for web service than phone service, indicating that those states better utilize their websites to communication information. In contrast, some states (New Jersey and Washington) still rely heavily on the phone to communicate information, as indicated by a much higher mean score for phone service than web service.

In a rapidly changing world of information technology, more and more consumers and family members will rely on the web, but our survey results confirm that states have been slow to adapt. State mental health authorities need to take advantage of the new technology and put more resources into their web-based systems. And, in this time of limited staff resources, enhanced information on websites can help to relieve the burden on phone personnel within state mental health authorities in answering frequently asked questions.

Additionally, states should be mindful of using technologies that the general public have available to them, rather than esoteric or sophisticated technologies. As an example, some raters were frustrated by the large quantity of website documents that could only be accessed as PDF files. Their computers did not have the required technology to open these documents.

• Intra-state inconsistency with respect to phone service personnel responses
Inconsistency within state phone services was an issue in general for consumers and family members. For example, in over half the states, phone personnel within the state mental health authority requested a zip code, mailing address, and /or county before providing information and referral services. However, within those same states, other raters had a different experience when requesting information and were not asked to provide a zip code, mailing address, and/or county, indicating that phone personnel within states may not be dealing with calls in a consistent way. Another example of intra-state inconsistency is captured by this common situation: Two raters left voicemails for the same staff person, and only one of those raters received a call back.

• Communication between phone carriers and state mental health authorities needs improvement
Raters complained numerous times that phone carriers (e.g. Information, 411) gave them the wrong numbers for state mental health authorities, even when raters gave these phone carriers the name of the city in which the state mental health authority was based. Oftentimes, raters called these phone carriers a few times, yet multiple phone calls did not always yield the correct phone number. State mental health authorities should ensure that phone carriers have updated contact information

Following in this Appendix is a listing of each state's performance on the Consumer and Family Test Drive, including a breakdown of the phone and Web scores. For a more detailed analysis of the CFTD, visit www.nami.org.

Test Drive Score Results

State	Test Drive Score (out of 10 pts)	Mean Score Phone + Web (out of 40 points)	Mean Score Phone (out of 40 points)	Mean Score Web (out of 40 points)	Total # of surveys collected
1. Tennessee	10	24.75	28.00	21.50	8
2. Ohio	10	23.88	28.75	19.00	8
3. Indiana	10	23.57	32.00	17.25	7
4. South Carolina	10	22.33	21.33	23.33	6
5. Michigan	10	21.50	22.67	20.33	6
6. West Virginia	10	21.50	23.50	19.50	4
7. Rhode Island	9	20.25	30.00	10.50	4
8. Connecticut	9	20.17	24.00	16.33	6
9. Wyoming	9	20.00	22.75	16.33	7
10. Minnesota	9	19.75	17.75	21.75	8
11. Alaska	8	19.57	15.00	23.00	7
12. Florida	8	18.75	22.50	15.00	4
13. New Jersey	8	18.67	30.67	6.67	6
14. Oregon	8	18.00	16.00	20.00	4
15. Maryland	8	18.00	27.50	8.50	4
16. New York	7	17.83	14.00	21.67	6
17. Mississippi	7	17.75	18.50	17.00	8
18. North Carolina	7	17.63	23.75	11.50	8
19. Maine	7	17.33	19.00	15.67	6
20. Washington DC	7	17.25	20.00	14.50	4
21. Utah	7	17.00	21.50	12.50	8
22. New Hampshire	6	16.63	14.50	18.75	8
23. Arizona	6	16.50	23.00	10.00	6
24. California	6	16.00	12.00	20.00	6

State	Test Drive Score (out of 5 pts)	Mean Score Phone + Web (out of 40 points)	Mean Score Phone (out of 40 points)	Mean Score Web (out of 40 points)	Total # of surveys collected
25. Georgia	6	16.00	16.75	15.25	8
26. Hawaii	6	15.33	22.00	8.67	6
27. Texas	5	14.75	8.00	21.50	4
28. Wisconsin	5	14.60	14.00	15.00	5
29. Oklahoma	5	14.25	16.75	11.75	8
30. Massachusetts	5	14.17	7.33	21.00	6
31. Vermont	5	14.00	10.67	16.50	7
32. Delaware	4	13.88	20.50	7.25	8
33. Colorado	4	13.50	23.50	3.50	4
34. Iowa	4	13.38	20.75	6.00	8
35. Washington	4	12.80	25.00	4.67	5
36. Montana	4	12.63	18.00	7.2	8
37. Nebraska	3	12.14	12.00	12.25	7
38. Virginia	3	11.38	16.75	6.00	8
39. Idaho	3	11.33	13.00	9.67	6
40. Nevada	3	11.17	11.33	11.00	6
41. Kansas	3	11.0	5.00	17.00	6
42. Pennsylvania	2	10.50	19.33	1.67	6
43. Louisiana	2	10.33	6.67	14.00	6
44. North Dakota	2	10.17	10.33	10.0	6
45. Kentucky	2	8.50	6.00	11.00	6
46. Illinois	2	7.50	10.00	5.00	6
47. Arkansas	1	7.13	8.50	5.75	8
48. New Mexico	1	6.67	10.00	3.33	6
49. South Dakota	1	6.00	2.00	8.67	5
50. Missouri	1	5.50	6.00	5.00	8
51. Alabama	1	3.38	2.00	4.75	8

NAMI Instrument Used for Consumer and Family Test Drive

NAMI's Consumer and Family Test Drive of Accessible Information from the State Mental Health Authority

Name of person completing this form: Date:

US State surveyed:

Conducted *(please mark one)*: Phone Website

How would you describe yourself? *(Please check box that best describes your work for this survey)*:

❑ Consumer ❑ Family member

Did you have to ask NAMI NH for the website address or phone number of the State Mental Health Authority?

❑ Yes ❑ No

If phone survey, did you leave a voice message, and not hear back within 24-48 hours?

❑ Yes ❑ No

If phone survey, did you leave a second voice message, and not hear back within 24-48 hours again?

❑ Yes ❑ No

Start Time: Finish Time:

Names/Positions of people with whom you spoke on the phone *(if available)*:

1.

2.

3.

4.

Survey

Please indicate how easy it was to find or obtain information from the State Mental Health Authority on the following topics. If you were unable to find or obtain any information on a particular topic in 2-3 minutes, check the box that reads, "No information found" and go on to the next question.

	0	1	2	3	4	Comments
I can find information from the State Mental Health Authority on…	No info found	With great difficulty	With some difficulty	Easily	Very easily	Indicate additional information here (described in Directions)
1.Where to go for help for mental illness						
2.The treatment of severe mental illness (schizophrenia, bipolar disorder, major depressive disorder)						
3. Treatment for co-occurring disorder (having both a mental illness and a substance abuse disorder)						
4. Supported housing						
5. How to apply for Medicaid						
6. The process of involuntary commitment to inpatient care (state psychiatric hospital)						
7. Mental illnesses and their treatment in a non-English language						
8. How to communicate feedback or complaints to the State or County Mental Health Authority						
9. Medications for the treatment of mental illness						
10. Recovery and wellness promotion (quitting smoking, exercise, managing medications, etc.)						