NAMI National's 2008 Consumer & Family Test Drive of Accessible Information from the State Mental Health Authorities Procedures, Methodology, and Discussion

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Purpose

The purpose of this study was 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. In order to assess this ease of access, project staff developed a brief survey. Domains used to develop survey items in this instrument were based upon the NAMI National questionnaire associated with the larger project.

Survey

The survey included 10 items pertaining to mental health issues, rated on a Likert scale of 0-4, where 0 represented "no info 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," and 4 represented information that was found "very easily." The maximum total score per survey was 40 points. Survey items were basic and included information on "where to go for help for mental illness," "recovery and wellness promotion," and "how to apply for Medicaid." The intention was to have two family members and two consumers survey each state. Each rater would survey a state twice, one survey of the state's website and one survey of the state's phone service, for a total of 8 surveys per state.

Raters

Consumers were recruited from the group of NAMI NH's "In Our Own Voice" program presenters. Family members were individuals who had previously participated in NAMI NH programs, classes, or other activities. Since these consumers and family members have already volunteered much of their time toward mental health education and awareness, we thought that it was highly probable that they would be able to donate the considerable time necessary to complete the test drive surveys. In the end, 9 consumers were recruited, and 9 family members were recruited. All participants were asked to survey at least 10 states each. 4 family members and 3 consumers were each asked to take on additional surveys that were either unassigned initially, or that other participants had been unable to complete. Participants received a stipend when their completed surveys were received, and were also reimbursed for expenses incurred while completing the surveys (e.g., postage and phone bills).

Inter-rater Reliability Training

In order to ensure inter-rater reliability, a two-hour orientation was held for all participants. Individuals who were unable to attend were required to speak with the NAMI NH Research staff by phone or in person so that a one-on-one orientation could be conducted. One-on-one orientations were provided to four participants. Raters were all trained under the same set of directions. The training attended to issues like: How to search for a state mental health authority's website, when to consult the provided "cheat sheet" (NAMI NH provided phone 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. Training emphasized that actual information obtained need not be written down. The survey was mainly looking for raters' numerical rating of ease of accessing this information. Raters received their survey kits and state assignments at the end of the orientation training.

Data Collection

The data collection period ran 7 weeks, from the end of September to early November, 2008. Throughout the data collection period, project staff provided extensive phone technical assistance to raters. Raters' concerns focused on: what to do about the need for a zip code or mailing address in order to access state information; website documents were in an electronic application that they could not open on their computers (e.g. PDF files); state mental health authorities were not returning their calls. Project staff provided consistent answers to raters' concerns.

In all, 404 surveys were collected out of a possible 404. All state surveys had consumer and family member representation resulting in a total of 8 surveys per state being completed.

Scoring

Although the surveys assessed much more than simply the quantitative ratings for the 10 items (survey completion time; names of people that raters spoke with, for example), the final report focuses mainly on the quantitative scores. However, the final report includes brief anecdotal information on each state, regarding both positive and negative comments that raters made about their website and phone service experiences.

The final report includes the Test Drive score (out of 10 points), the Mean Score, upon which the Test Drive score was based and which includes both phone and web surveys (out of 40 points), An additional score was calculated, which will be referred to as the "Extent of Difference Between a State's Phone and Website Score". This is calculated by subtracting each state's Web score from its Phone score. Therefore, positive values indicated that the state's phone service scored higher than its website, and negative values indicated that the state's website scored higher than its phone service. This is an important variable to compute, as some states experienced wide gaps between their different information sources. For example, New York scored 10 out of 10 points for the Test Drive, but this was only because its phone service was so superior (28.17 as opposed to a Web score of 10.50). These differences may be a reflection of what medium a state emphasizes when providing customer information, or the fact that the state has not yet put resources into its web-based system to provide customers with information about its services.

Additional, the final report displays the means table for all individual survey items. These means are based off of both phone and website surveys. This kind of information is helpful in terms of assessing which items generally scored high or low across states. For example, the item assessing access to information in a non-English language had the lowest-scoring mean out of all survey items, pointing toward a general lack of recognition for assuring language diversity in the information system.

A state's Test Drive score represented 10% or 10 points of its overall Final State Score, which NAMI National calculated based upon other data collected. The Test Drive 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. The top 5 states received 10 points for their Test Drive score, the next 5 received 9 points for their Test Drive score, and so on until the last group of 5 scoring 1 point. In one case 6 states were included in one group due to tie scores.

Scores from the 2005 Consumer and Family Test Drive have been included when available for comparison purposes.

National Trends & Recommendations

The scoring process revealed some general trends across states:

- *Inadequate phone and website accessibility*

  Across states, the average survey score, out of a possible 40 points, was 17.32 points (sd= 10.42). Only 16 state scored 20 points or more out of the possible 40 points, meaning that over 68% of states did not even acquire *half* of the points possible. This distribution of scores indicates that both consumers and family members felt frustrated by their inability to access information from either the state's website or phone information service. Surveyors indicated having to do multiple call backs before they got a response which also increase their frustration. This frustration only adds to the burden of mental illness, and does not empower consumer or family members with the information that they need to play an active role in their treatment. Greater emphasis should be placed on enhancing consumer and/or family member access to a state's information service system; making initial contact with the public mental health service system easy, friendly, and informative for consumers and family members will add to the likelihood of better satisfaction with services.

- *Information systems lack cultural sensitivity*

  As indicated in the bullet above, accessibility to information on mental health is inadequate for the majority population. According to the Test Drive results, accessibility to this information is even more problematic for culturally and linguistically diverse, and underserved populations. One Test Drive survey item assessed ease of access to information on mental illnesses and their treatment *in a non-English language*. During training, we told raters to use a broad definition of "non-English speaker," including those who were deaf and hard of hearing, as well as those who were blind. Out of the 10 survey questions, the mean for this item (including both phone and website surveys) was the second lowest overall (1.40 points out of a possible 4, sd= 1.23), indicating that information could be found in a non-English language *only with great difficulty*. States need to move towards building more culturally sensitive and linguistically diverse information systems, so that diverse populations already encountering a wide range of barriers to care can become informed consumers and more likely be able to access the services that they need.

Individual states' mean scores for this survey item indicate that some states are already moving in a culturally competent direction. It is encouraging that most states with known diverse populations scored at or above the mean. For example, Virginia had a mean score of 3.13 (sd=1.18), Massachusetts 2.88 (sd=1.31), Tennessee 2.88 (sd=0.85), Texas 2.38 (sd=1.11), and New York 2.25 points (sd=1.88). Unfortunately, several states with known diverse populations scored well below the mean. California had a mean score of 1.13 points (sd=1.44), Georgia 1.13 (sd=1.03), Maryland 1.13 (sd=0.85), Florida 0.88 (sd=1.03), and New Mexico 0.75 points (sd=.96). The large standard deviations for many of these states' scores indicate variability in raters' experiences of searching for information directed towards diverse populations. Therefore, when states are able to provide information to non-English speakers, they need to ensure that the information is easy to find on their website homepages, and that phone personnel are clearly trained in how to connect non-English speakers to information in their language/interpreter services.

- *Phone services are superior to websites*

  Mean Phone Scores were significantly greater than Mean Web Scores [$t(201) = -3.91$, $p=.001$]. On average, states scored 19.60 points (sd= 15.64) on their phone surveys, and 15.03 points (sd= 10.51) on their website surveys. As more consumers and family members rely on the web for information, states need to take advantage of the new technology and put more resources into building and enhancing their web-based systems. It is important for states to have a wide range of information on their websites, since phone personnel frequently do not have the time to answer a series of questions that cover a breadth of subjects, such as the Test Drive questions. Some states referred surveyors to other personnel that did have the information requested. 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 with broken links or missing pages.

- *State agency responses to phone survey*

  Multiple surveyors reported reaching individuals who had already responded to the NAMI National Consumer and Family Test Drive survey. This may imply that the mental health authorities in those states relatively small for multiple participants to have reached the same individuals, or that those states have very specific referral protocols in place when responding to surveys/the topics covered on this survey

- *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. One time the surveyor was incorrectly referred to the state's Department of Corrections, who did supply the correct agency to contact. State mental health authorities need to make sure that they are updating their current contact information to phone carriers.

- *NAMI National and state NAMI affiliates appear as a resource*
  Several surveyors were provided NAMI National and NAMI state web and phone contacts information as the source to answer the Test Drive questions.

- *2005 rankings compared to 2008*
  It is worth noting that the top 5 (VA, MA, CT, ME, TN) ranked states in '08, except for one (Tennessee) made significant gains from '05.
  Of the bottom 5 ranked states (AR, CA, WA, OR, NM) in '08 three were new entries from much higher scores in '05 and two remained on the bottom.

- *Individual item Rankings 2008*
  In this survey where to go for help had the highest mean score (2.45). The mean web score for this item (2.67) was substantially higher than for any other item on the survey. The lowest mean score on the individual items was where to go for information on medications for treatment of mental illness= 1.22.