SPOTLIGHT

Engaging Peers in the Evaluation: A Model for Measurement

In the winter of 2019, the Help@Hand program completed the important work of defining and selecting the measurement constructs to assess mental health stigma.

A panel of five community Peers, individuals with lived experience and/or family member experience, and six academics with expertise in developing stigma measures was convened. The panel came to consensus on the dimensions of stigma that were important to measure as part of Help@Hand, specifically the following three areas:

1) **Internalized stigma:** one's own stigma toward their mental health condition;
2) **Resilience:** one's hope and positive attitude toward living with or recovering from one's mental health condition; and
3) **Mental health treatment stigma:** one's stigma toward seeking treatment for one's mental health condition.

The result of the effort was to identify 28 questions to be incorporated in the Help@Hand evaluation:

Background:

There are many measures of mental health stigma that focus on the broad perspectives of the stigmatizer versus the perspectives of the stigmatized. A community participatory approach was adopted in late 2019 to select the guiding instruments for the Help@Hand program. The effort ensured that the instruments:

1) were sensitive to the type of impact expected of Help@Hand apps;
2) met the stigma dimensions of interest of counties/cities; and
3) were scientifically valid.

DOMAIN / SCALE		SUBSCALE	ITEMS
Internalized Stigma	ISMI	Alienation	I feel out of place in the world because I have a mental illness Having a mental illness has spoiled my life People without mental illness could not possibly understand me I am embarrassed or ashamed that I have a mental illness I am disappointed in myself for having a mental illness I feel inferior to others who don't have a mental illness
		Social Withdrawal	I don't talk about myself much because I don't want to burden others with my mental illness I don't socialize as much as I used to because my mental illness might make me look or behave 'weird' Negative stereotypes about mental illness keep me isolated from the 'normal' World Stay away from social situations in order to protect my family or friends from embarrassment Being around people who don't have a mental illness makes me feel out of place or inadequate I avoid getting close to people who don't have a metal illness to avoid rejection
Resilience	RAS-R	Willingness to ask for help	I know when to ask for help I am willing to ask for help I ask for help when I need
		Not dominated by symptoms	Coping with my mental illness is no longer the main focus of my life My symptoms interfere less and less with my life My symptoms seem to be a problem for shorter periods of time each time they occur
Mental Health Treatment Stigma	SSOSH		I would feel inadequate if I went to a therapist for psychological help My self-confidence would NOT be threatened if I sought professional help Seeking psychological help would make me feel less intelligent My self-esteem would increase if I talked to a therapist My view of myself would not change just because I made the choice to see a therapist It would make me feel inferior to ask a therapist for help I would feel okay about myself if I made the choice to see professional help If I went to a therapist, I would be less satisfied with myself My self-confidence would remain the same if I sought professional help for a problem I could not solve I would feel worse about myself if I could not solve my own problems

Tehama County, in their pilot launch of myStrength, included the reduction of mental health stigma as an anticipated primary outcome of their technology implementation. The Tehama team turned to the work of tailoring their survey instruments to include items to measure mental health stigma in order to capture changes.

Led by Travis Lyon, Mental Health Services Act Coordinator, Behavioral Health, and in partnership with Ron Culver, Northern Valley Catholic Social Service (NVCSS) Supervisor, Tehama County Peer Programs, and a team of participating Peers, a workgroup was developed. This workgroup identified and commented on the limitations of the provided items that had been identified in the prior year.

Two primary limitations of the recommended survey items were identified by the workgroup. The first limitation was the overall length of the recommended items. Given the demographic questions that Tehama planned to include, surveys needed to be kept short to ensure that they could be reasonably completed. The second limitation was the lack of inclusivity and potential offensive wording of some of the items in the scales. For example, the surveys items were developed and guided by evidence-based practices to maximize the reliability and validity of the survey instruments. The Peers, however, were uncomfortable with some of the wording choices. Including questions with words like looking "weird" or "having one's life spoiled" were noted as potentially being stigmatizing themselves.

> *The reason the Peers and I wanted to include all three areas of internalized stigma, resilience, and mental health treatment seeking stigma is because they all go hand in hand. Internalized stigma, the belief that there is "something wrong with me," can lead to not seeking treatment; "there is something wrong with me because I need help," which in turn makes it very difficult to foster any sense of resilience, making it exceedingly challenging to break the cycle.*
>
> – **Ron Culver**, *Northern Valley Catholic Social Service (NVCSS) Supervisor, Tehama County Peer Programs*

With guidance from the Help@Hand evaluation team, the Peer workgroup sought to understand and respond to these limitations. Three areas were explored by the workgroup:

1. Which stigma topics/constructs, if any, were important to include in their evaluation?
   a) Internalized Stigma (subtopics: Alienation, Social Withdrawal)
   b) Resilience (subtopics: willingness to ask for help; not dominated by symptoms)
   c) Mental Health Treatment Seeking Stigma
2. How many questions did they want to include in their survey? What was feasible and appropriate when considering respondent burden?
3. What wording options seemed best for promoting cultural competency and inclusiveness?

The next step involved selecting the specific items to be used for each area of inquiry. To facilitate the discussion, the evaluation team shared data collected as part of the Help@Hand evaluation around survey wording and measurement with the Tehama workgroup. The workgroup reviewed the scree plot analysis for each construct to see how many unique groups of questions were present in each scale.

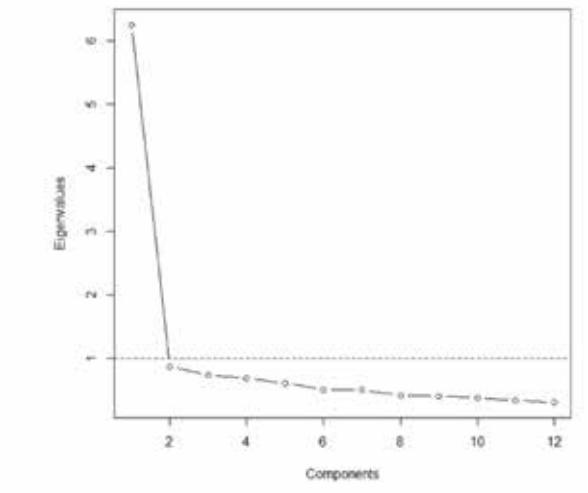

Figure 1: Scree plot for the 12 items of the ISMI section

Figure 1 shows the scree plot for the 12-items that are part of the ISMI scale. A scree plot displays how much variation each component captures from the data. The general rule, when using a scree plot, is to drop the components after the one starting the elbow. As shown in the figure, the scree plot indicated that there was one significant cluster (or group of items) and perhaps a second less meaningful cluster.

The workgroup then walked through different ways to consider the influence of each individual item on the total scale – or the item total correlation. For example, this was done by creating a total score for each scale, and then correlating each item's score with the total score (at the participant level).

Table 1 shows an example of Item I12 (which came from the social withdrawal subscale), which had the highest item total correlation with the ISMI scale (0.79), and that all the items had a relatively high total correlation (r >.5).

Table 1

7.1 The ISMI items

- I1: I feel out of place in the world because I have a mental illness.
- I2: Having a mental illness has spoiled my life.
- I3: People without mental illness could not possibly understand me.
- I4: I am embarrassed or ashamed that I have a mental illness.
- I5: I am disappointed in myself for having a mental illness.
- I6: I feel inferior to others who don't have a mental illness.
- I7: I don't talk about myself much because I don't want to burden others with my mental illness.
- I8: My mental illness might makes me look or behave "weird".
- I9: Negative stereotypes about mental illness keep me isolated from the 'normal' world.
- I10: I stay away from social situations in order to protect my family or friends from embarrassment.
- I11: Being around people who don't have a mental illness makes me feel out of place or inadequate.
- I12: I avoid getting close to people who don't have mental illness to avoid rejection.

Ranks	California dataset		Other States dataset	
	Item and category	Correlation with the ISMI total score	Item and Category	Correlation with the ISMI total score
1	I12(Social Withdrawal)	0.79	I12(Social Withdrawal)	0.80
2	I9 (Social Withdrawal)	0.77	I11 (Social Withdrawal)	0.77
3	I11(Social Withdrawal)	0.76	I9(Social Withdrawal)	0.77
4	I10(Social Withdrawal)	0.76	I10(Social Withdrawal)	0.76
5	I6 (Alienation)	0.76	I8 (Social Withdrawal)	0.74
6	I8 (Social Withdrawal)	0.75	I6 (Alienation)	0.74
7	I4 (Alienation)	0.73	I5 (Alienation)	0.74
8	I2 (Alienation)	0.73	I4 (Alienation)	0.72
9	I5 (Alienation)	0.71	I2 (Alienation)	0.70
10	I1 (Alienation)	0.68	I1 (Alienation)	0.67
11	I7 (Social Withdrawal)	0.62	I7 (Social Withdrawal)	0.64
12	I3 (Alienation)	0.60	I3 (Alienation)	0.59

In addition to considering the psychometric properties of each item, the Peer Workgroup also balanced their item selection by considering the language used in each item.

The final selection of items included the following:

Original Item Wording (Peer Selected)

1. Internalized Stigma (ISMI)
   A. Alienation
      1) I4: I am embarrassed or ashamed that I have a mental illness.
      2) I6: I feel inferior to others who don't have a mental illness.
      3) I2: Having a mental illness has spoiled my life.
   B. Social Withdrawal

1) I7: I don't talk about myself much because I don't want to burden others with my mental illness.
2) I11: Being around people who don't have a mental illness makes me feel out of place or inadequate.
3) I12: I avoid getting close to people who don't have mental illness to avoid rejection.

2. Resilience (RAS-R) - Willingness to ask for help and not dominated by symptoms
   1) R1: I know when to ask for help.
   2) R5: My symptoms interfere less and less with my life.
   3) R6: My symptoms seem to be a problem for shorter periods of time each time they occur.
3. Mental Health Treatment Stigma (SSOSH) - Self-Perception concerning Treatment
   1) S2: My self-confidence would NOT be threatened if I sought professional help.
   2) S4: My self-esteem would increase if I talked to a therapist.
   3) S9: My self-confidence would remain the same if I sought professional help for a problem I could not solve.

Peer Driven Item Reduction and Wording

1. Internalized Stigma (ISMI)
   A. Alienation
      1) I4: I am embarrassed or ashamed that I have mental health challenges.
      2) I6: I feel inferior to others who don't have mental health challenges.
      3) I2: Having mental health challenges has spoiled my life.
   B. Social Withdrawal
      1) I7: I don't talk about myself much because I don't want to burden others with my mental health challenges.
      2) I11: Being around people who don't have mental health challenges makes me feel out of place or inadequate.
      3) I12: I avoid getting close to people who don't have mental health challenges to avoid rejection.
2. Resilience (RAS-R) - Willingness to ask for help and not dominated by symptoms
   4) R1: I know when to ask for help.
   1) R5: My symptoms interfere less and less with my life.
   2) R6: My symptoms seem to be a problem for shorter periods of time each time they occur.
3. Mental Health Treatment Stigma (SSOSH) - Self-Perception concerning Treatment
   1) S2: My self-confidence would NOT be threatened if I sought professional help.
   2) S4: My self-esteem would increase if I talked to a therapist.
   3) S9: My self-confidence would remain the same if I sought professional help for a problem I could not solve.

In sum, there are several learnings that came out of this process:

- Including Peers in the decision-making process around measurement in evaluation is critical for selecting appropriate evaluation items.
- Developing the necessary understanding to make such decisions takes time.
- The availability of data gathered as part of the Help@ Hand evaluation was critical for using a data-driven approach for shortening the survey instruments.
- When presented with materials that are explained using minimal jargon, it is possible for people with limited training in statistics to understand the core issues and be able to make informed and insightful decisions.
- Evaluation efforts must always find a balance between what is scientifically valid and what is feasible – a partnered Peer-driven approach is an effective strategy for striking this balance.

> *I believe it was an extremely worthwhile process. It was great to see how the Peers and the UCI team were willing to learn from each other, and how open the creative space was that allowed for a rich and meaningful dialogue. A genuinely enjoyable experience!*
>
> – **Ron Culver**, *Northern Valley Catholic Social Service (NVCSS) Supervisor, Tehama County Peer Programs*

The evaluation team wishes to extend a thanks to Travis for creating the time and space to do this work. We also wish to extend a special thanks to Ron and the Peers for so generously sharing their viewpoints and being open to learning about scale construction and item selection.