

# Conceptualizing and Measuring Mental Health Stigma

Resilience

Strength

Understanding

Grace

Education

# Conceptualizing and Measuring Mental Health Stigma

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**Recommended Citation:** Sorkin, D.H.; Mukamel, D.; Eikey, E.; Mark, G.; Schueller, S.M.; Schneider, M.; Stadnick, N.; Zheng, K.; Borghouts, J.; Davis, K.; De Leon, C.; Macias, D.; Mathew, A.B.; Palomares, K.; Myrick, KJ. (2020). Conceptualizing and Measuring Mental Health Stigma. Program of Research in Translational Technology Enabling High Quality Care, University of California, Irvine.

This report was prepared for the Mental Health Services Act approved Innovation Technology Suite Project (INN Tech Suite Project) called Help@Hand under contract number 417-ITS-UCI-2019.

## Acknowledgements:

The Help@Hand evaluation team wishes to acknowledge and thank the participating Taskforce Members for their participation in this effort. The Help@Hand evaluation team would also like to thank Charitable Ventures for designing this report.

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## Introduction

The Innovation Technology Suite Project (branded as Help@Hand in 2019) is a five-year<sup>1</sup> statewide collaborative demonstration project funded by the California Mental Health Services Act (also known as Prop 63) and has a total budget of approximately \$101 million. It is designed to bring interactive technology-based mental health solutions into the public mental health system through a highly innovative set (or “suite”) of mental health digital therapeutics. The project intends to provide Californians with free access to mental health digital therapeutics designed to provide: education on the signs and symptoms of mental illness, including emotional/behavioral changes in mental health and symptoms; connection to help in real-time; and access to mental health services when needed. In addition, Help@Hand leads innovation efforts by integrating Peers<sup>2</sup> throughout the project.

Through these efforts, Help@Hand focuses on five shared learning objectives:

- 1  
Detect and acknowledge mental health symptoms sooner;
- 2  
Reduce stigma associated with mental illness by promoting mental wellness;
- 3  
Increase access to the appropriate level of support and care;
- 4  
Increase purpose, belonging, and social connectedness of individuals served;
- 5  
Analyze and collect data to improve mental health needs and service delivery.

Evaluation of Help@Hand’s second shared learning objective – “Reduce stigma associated with mental illness by promoting mental wellness” – requires the ability to measure mental health stigma prior to and after the implementation of the project. The Help@Hand evaluation team, therefore, has reviewed the literature to identify potential measures to assess this learning objective. A 2018 review of the literature found more than 400 measures of mental health stigma. Only one-third of these measures had been psychometrically evaluated (Fox et al, 2018). Those measures addressed different aspects of stigma which were of varying relevance to the Help@Hand project. Therefore, the evaluation team developed a process to identify measures that are validated, relevant, and appropriate for measuring the expected impact of the Help@Hand project.

<sup>1</sup> The project was originally designated as a 3-year effort.

<sup>2</sup> Help@Hand defines a Peer as a person who publicly self-identifies with having a personal lived experience of a mental health/co-occurring issue accompanied by the experience of recovery. A Peer has training to use that experience to support the people they serve.

A Taskforce of 11 experts was convened to recommend mental health stigma measures for the Help@Hand evaluation. This process followed three guiding principles:

- 1 Use a community participatory process by involving Peers, County/City mental health professionals, and scholars in the field of mental health stigma measurement and survey development
- 2 Include a review of existing and published mental health stigma measures that considered the advantages and disadvantages of each measure for Help@Hand
- 3 Facilitate consensus among the Taskforce using an adapted Delphi method<sup>3</sup> to recommend the best measures for the Help@Hand evaluation

The Taskforce met for a workshop in October 2019 at Lake Arrowhead, California for two days of learning and discussion on: the meaning of mental health stigma and its impact on different stakeholders; mental health stigma research and measurement; and implications of these issues for conceptualizing and measuring mental health stigma in the context of the Help@Hand project. Taskforce members also participated in discussions on how the different dimensions of mental health stigma relate to Help@Hand. Following the two-day workshop, the Taskforce continued discussions in order to identify and recommend specific measures using the adapted Delphi method to reach consensus.

This report describes the process of identification and recommendation of mental health stigma measures which led to the measure to be included in the Help@Hand evaluation. The report includes:

- I. Workshop Summary
- II. Post-Workshop: From Stigma Dimensions to Stigma Measures
- III. Proposed Measurement Models
- IV. Learnings and Recommendations

<sup>3</sup> Developed by the RAND Corporation in the 1950s, the Delphi method allows a group of experts to reach consensus. It involves asking the group to give anonymous feedback on questionnaires. The facilitator then provides summarized feedback to the group. The process continues until consensus occurs.

# SPOTLIGHT: INSTRUMENTS USED IN RECENT EFFORTS IN CALIFORNIA TO REDUCE MENTAL HEALTH STIGMA AND DISCRIMINATION



There are many stigma reduction programs across the nation (Corrigan & Shapiro, 2010). In 2004, the Mental Health Services Act (Prop 63) was passed in California and created 25 programs that were derived from the California Strategic Plan on Reducing Mental Health Stigma and Discrimination.

The California Mental Health Services Authority (CalMHSA) oversees one of the largest efforts in the United States in prevention and early intervention (PEI) programs to improve mental health (Collins, Wong, Roth, Cerully, & Marks, 2015). CalMHSA implemented three statewide PEI initiatives in California with a focus on mental illness stigma and discrimination reduction, suicide prevention, and student mental health. CalMHSA selected the RAND Corporation, a nonprofit research organization, to evaluate these efforts.

In 2013, CalMHSA implemented a statewide stigma and discrimination reduction initiative called “Each Mind Matters” to improve the mental health of Californians (Collins, Wong, Roth, Cerully, & Marks, 2015). The California Statewide Survey (CASS) was utilized to report findings from this initiative. The CASS was developed to track attitudes, beliefs, and behaviors related to mental illness (Collins, Wong, Roth, Cerully, & Marks, 2015). It is a longitudinal survey conducted over the phone with California adults ages 18 years and older. Baseline data was compared to follow up data a year later.

Key findings in the follow-up survey indicated there may have been an increase in recognition and acceptance of mental health problems. More Californians provided great support to individuals with mental illness and stated they were willing to socialize with, live next to, and work with people with mental illness (Collins, Wong, Roth, Cerully, & Marks, 2015). No other stigma initiative has used this survey in its evaluation.

Additionally, RAND developed the California Well-Being Survey (CWBS) to evaluate PEI programs. This survey was designed to track the impact of these PEI programs of the targeted populations. The CWBS assesses perceptions of public stigma, experiences of self-stigma and discrimination, treatment and recovery beliefs, and exposure to anti-stigma activities and messages. It measures self-stigma, specifically alienation and public stigma (Wong, Collins, Cerully, Roth, & Marks, 2015). It is the first population-based survey of those who are at risk or are experiencing mental health concerns, but may not recognize that they have a mental health concern or may not have received treatment. Many of these efforts have been able to increase recognition and acceptance of mental health problems.

Other tools exist to evaluate the three statewide PEI programs. The MOQA (Measurements, Outcomes, and Quality Assessment) is a county-driven and state-supported effort to improve statewide reporting on outcomes resulting from programs supported through the Mental Health Services Act. This tool focuses on data collection for the Suicide Prevention and Stigma and Discrimination Reduction programs. The two surveys used for these data collection are the Suicide Prevention Participant and the Stigma and Discrimination Reduction Program Participant Questionnaire.

In addition to the PEI programs, another recent program, the California Reducing Disparities Project (CRDP), was established in 2009 to achieve mental health equity in California (“The California Reducing Disparities Project | California Pan-Ethnic Health Network,” 2020). Its focus has been on providing population specific information on mental health challenges and community-based solutions. The California Communities Mental Health Services Survey (CCMHSS) measures stereotypes and anticipated stigma.

Thus, various efforts across California evaluated mental health stigma based on their program-specific goals.

## Workshop Summary

In October 2019, a Taskforce of five community Peers and individuals with lived experience and/or family member experience, as well as six academics with expertise in developing stigma measures was convened for an intensive two-day workshop titled “Conceptualizing and Measuring Mental Health Stigma for Evaluation.” Workshop Taskforce attendees included program managers, peer support specialists, professors of psychology and psychiatry, social and clinical psychologists, senior research scientists, and was staffed by members of the Help@Hand evaluation team. **Appendix A** includes bios of the workshop speakers and attendees.

### The workshop objectives were to:

- 1 Bring together mental illness stigma experts – including individuals with lived experience and/or family member experience and researchers – to share experiences and perspectives about stigma
- 2 Understand the ways in which mental illness stigma is conceptualized in both the scientific literature and in practice
- 3 Begin the development of a conceptual framework for assessing mental illness stigma for the Help@Hand evaluation

The workshop agenda is shown in **Figure 1**. Agenda items included a keynote addresses on defining and measuring mental illness stigma, Taskforce discussions, presentations of different perspectives on stigma from the research literature, and a conversation about recovery in the digital age. In addition, existing scales and survey items used to measure mental illness stigma were discussed among conference attendees, with a thorough examination of the strengths and weaknesses of measuring certain types of stigma and of the existing measures.

**Figure 1. Workshop Agenda**

AGENDA	
TIME	AGENDA ITEM
THURSDAY OCTOBER 17th 2019	
9:00AM-10:00AM	<ul style="list-style-type: none"> <li>• Introductions</li> <li>• Overview of Help@Hand Project</li> </ul>
10:00AM-12:00PM	<ul style="list-style-type: none"> <li>• Panel Discussion: Let's Stick it to Stigma               <ul style="list-style-type: none"> <li>o Kick-Off: Keris Myrick</li> <li>o Reading: Kelechi Ubozoh</li> <li>o Panel:                   <ul style="list-style-type: none"> <li>• James Clement</li> <li>• Shannon McCleerey-Hooper</li> <li>• Keris Myrick</li> <li>• Pamela Norton</li> <li>• Vanessa Ramos</li> <li>• Kelechi Ubozoh</li> <li>• Facilitator: Jennifer E. Boyd</li> </ul> </li> </ul> </li> </ul>
12:00PM-1:00PM Lunch will be served	<ul style="list-style-type: none"> <li>• Measuring the Stigma of Mental Illness               <ul style="list-style-type: none"> <li>o Patrick Corrigan</li> </ul> </li> </ul>
1:00PM-2:30PM	<ul style="list-style-type: none"> <li>• Reflection and Sharing through Art</li> </ul>
2:30PM-5:00PM	<ul style="list-style-type: none"> <li>• Perspectives from the research literature               <ul style="list-style-type: none"> <li>o Research on Internalized Stigma in Serious Mental Illness                   <ul style="list-style-type: none"> <li>• Jennifer E. Boyd</li> </ul> </li> <li>o Defining and Measuring Stigma: Learnings from Other Identities and Health Conditions                   <ul style="list-style-type: none"> <li>• Valerie Earnshaw</li> </ul> </li> <li>o Mental Health Stigma in Military Veterans: What is it, Where Does It Come from, and How does it Impact Veterans' Treatment Seeking?                   <ul style="list-style-type: none"> <li>• Dawne Vogt</li> </ul> </li> <li>o California Initiatives: Research for Stigma Reduction Past, Present, Future                   <ul style="list-style-type: none"> <li>• Alyssa Ghirardelli</li> </ul> </li> <li>o Facilitator: Dara Sorkin</li> </ul> </li> </ul>
FRIDAY OCTOBER 18th, 2019	
9:00AM-9:15AM	<ul style="list-style-type: none"> <li>• Overview of the Day               <ul style="list-style-type: none"> <li>o Dara Sorkin</li> </ul> </li> <li>• Recovery in the Digital Age               <ul style="list-style-type: none"> <li>o Keris Myrick</li> </ul> </li> </ul>
9:15AM-10:15AM	<ul style="list-style-type: none"> <li>• Keynote Address: Defining and Measuring Mental Health Stigma               <ul style="list-style-type: none"> <li>o Annie Fox</li> </ul> </li> </ul>
10:30AM-12:00PM	<ul style="list-style-type: none"> <li>• Discussion: Good measurement properties and desirable characteristics               <ul style="list-style-type: none"> <li>o Facilitator: Dawne Vogt</li> </ul> </li> <li>• Identification and prioritization of measures with consensus building and group recommendation</li> </ul>
12:00PM – 1:00PM	<ul style="list-style-type: none"> <li>• Lunch</li> </ul>
1:00PM – 3:00PM	<ul style="list-style-type: none"> <li>• Open working session</li> </ul>

The following are key takeaways from these presentations and discussions. **Appendix B** provides a glossary for various stigma-related terms described in this section.

## Let's Stick It to Stigma: Taskforce Discussion

The workshop opened with understanding mental illness stigma from the perspective of individuals with lived experience.

Keris Myrick, MS, MBA, began the session with a dynamic presentation on how mental illness and individuals with lived experience and the general public, are portrayed, particularly in the media. It highlighted the importance of challenging media outlets to not only consider the impact of its messages on individuals with lived experience and the general public, but also as venues for sharing informed knowledge and setting social expectations. In addition, the presentation shared a brief history of mental illness and stigma from the 1920s to present day. It also discussed seeing mental illness through a lens of inclusion, not exclusion and segregation, where people can be seen depending on where they are and included in society rather than hospitalized and segregated. The presentation ended with a powerful reminder that people are humans first; **people are not defined by a diagnosis.**



Following the presentation, Kelechi Ubozoh shared excerpts from her book, "We've Been Too Patient: Voices from Radical Mental Health." The excerpts highlighted stories of embracing someone's experience and their impact, which set the stage for the ensuing discussion.

The Taskforce discussion included six people with lived experience and/or caregivers of people with lived experience, who provided their perspective of mental health stigma and mobile mental health technology. Participants were asked to describe why they got involved in the mental health field and what the words "reduce mental health stigma" meant to them. The Taskforce members also spoke to what excited them and intimidated them about using mobile mental health technology.

The Taskforce facilitator ended with the question: "What would the successful use of a mental health application look like?" **Some felt successful use of mental health technology would facilitate**

**connection – allowing users to feel welcomed and safe, while building a sense of community based on shared experiences. The discussion also touched on the apps ability to gather person-centered data, workforce barriers for those with mental illness, and an overall desire for the reduction in negative experiences and perspectives related to mental illness stigma.**





## Reflections and Sharing through Art



Taskforce attendees were invited to participate in a session titled “Reflections and Sharing through Art.” The purpose of the session was to allow for participants to process as well as share their thoughts and feelings in a non-conventional way. Attendees were provided paint and a blank canvas, and prompted to express what mental health/mental wellness/mental illness and the absence or presence of stigma meant to oneself.



The session was valuable in creating a space for trust between the diverse members of the Taskforce as well as encouraging creative expressions of what can be a complex and sensitive topic.

## Measuring the Stigma of Mental Illness: Keynote Address

Patrick Corrigan, PsyD, gave the keynote speech, which focused on understanding different kinds of measures and considerations when examining changes in stigma over time. As part of the keynote lecture, Dr. Corrigan specifically discussed the impact of different aspects of stigma: self-help stigma (stigma associated with seeking mental treatment), self-stigma (stigma a person has about their own mental illness), and public stigma (stigma that people have about those with mental illness). He also highlighted the importance of affirming attitudes rooted in recovery, empowerment, and self-determination.

*He also highlighted the importance of affirming attitudes rooted in recovery, empowerment, and self-determination.*

Dr. Corrigan discussed how some of the different stigma measures are designed to capture more process-related constructs, while others are designed to capture more outcomes-related constructs. He advised that the **instruments recommended for this project should be selected based on the aim(s) or evaluation questions to be answered.**

Additionally, the Taskforce was encouraged to **tailor the instrument selection for appropriate use in the population of interest (i.e., target audience), rather than selecting a generic or single-use instrument designed for the general population.** Finally, Dr. Corrigan suggested that the Taskforce should consider the **pros and cons of using certain terms related to mental illness or mental health** when working with vulnerable populations, such as veterans and transitional youth.

## Perspectives from the Research Literature

Presentations from four research perspectives were provided to participants as examples of prior studies that have conceptualized stigma in mental health, both in the literature and in practice. The four research perspectives included:

1

### Research on Internalized Stigma in Serious Mental Illness:

Jennifer E. Boyd, Ph.D., recently conducted research on internalized stigma, specifically that of severe mental illness and mental health providers with a lived experience of mental illness. **Internalized stigma is when a person feels stigmatizing messages about people with mental health problems is true of themselves. In other words, they stigmatize themselves.**

Dr. Boyd presented various types of internalized stigma related measures that could be considered for the Help@Hand evaluation and discussed how they should be phrased and structured. These types included: stereotype endorsement (believing stereotypes about mental illness); alienation (feeling set apart from others); social withdrawal (pulling away from contact with others due to concerns about the status of having a mental illness – not directly due to symptoms); discrimination experience (perceived exposure to discrimination); and stigma resistance (lack of stigma and ability to resist stigma).



## 2

## Defining and Measuring Stigma: Learnings from Other Identities and Health Conditions



Valerie Earnshaw, Ph.D., is a social psychologist who studies how stigma leading to health inequities among people living with a range of socially devalued characteristics and identities.

Based on her work evaluating measures of HIV stigma, her presentation listed the priorities identified when selecting a research measure for populations experiencing socially devalued characteristics as well as the specific HIV stigma indicators used. An emerging approach of measuring health-related stigma across traditionally siloed fields, such as HIV, tuberculosis, epilepsy, obesity, and mental illness, was also shared.

## 3

## Mental Health Stigma in Military Veterans: What is it, Where Does It Come from, and How does it Impact Veterans' Treatment Seeking?

Dawne Vogt, Ph.D., works in research that examines how societal stigma surrounding mental illness and mental health treatment might impact military veterans' treatment seeking.

Based on her research, Dr. Vogt's presentation revealed that engaging veterans in treatment is a substantial problem. She proposed that even anticipated stigma (the expectations of being the target of stereotypes, prejudice, and discrimination from others in the future) from unit members might impact currently serving military personnel to seek treatment. The presentation also included ways in which studies might suggest ideas for how to increase access and treatment seeking among the military veteran population.

## 4

## California Initiatives: Research for Stigma Reduction Past, Present, Future

Alyssa Ghirardelli, MPH, RD, studied maternal and child health, mental health stigma reduction, health equity and disparities, and obesity prevention.

Her presentation focused on the overall goal of several California Mental Health Initiatives to spark social change and stop stigma by way of storytelling and social marketing. She reviewed different evaluation projects and interventions, as well as the creation of a conceptual framework to guide methodology and measures.



## Recovery in the Digital Age

The second day of the workshop began with a presentation focused on learning about digital mental health technologies in order to better understand the Help@Hand project, which aims to implement such technologies, and the context of the evaluation. Keris Myrick presented on the use of mental health technology in recovery and shared her insights on selecting appropriate mental health apps. Ms. Myrick believed an important consideration is that an app should have a research base demonstrating its effectiveness. She also thought it is important for the individuals using the app to: 1) understand what they are looking for in an app (e.g., they might use apps to provide cognitive behavior therapy, symptom reduction, mood tracking, relaxation, or meditation); and 2) consider their preferences and how to incorporate the app into their daily lives (e.g., they might consider wearable technologies or using an app that provides instruction that meets their preferences). Ms. Myrick emphasized that people will only engage with an app for as long as they need it.

She then continued to highlight several options, including clinical and non-clinical technologies, social media platforms, and smartphones. For example, an individual can follow an automated bot on Twitter (self-care bots) and the bot can tweet self-care reminders. People may re-tweet these reminders so that others can engage in self-care. The presentation also noted that a smartphone, in its entirety, can be a tool -- not just in terms of a single app. For example, the smartphone's camera feature, reminder alarms feature, calendaring functions, texting, and rain/soothing sound apps can all be useful for reducing mental illness symptoms. A single app is not likely to be the only indicator of whether having access to a smartphone proves to be helpful.

The importance of integrating technology into clinical care was also discussed. Some potential users might initially consider mental health apps as strange or may have privacy concerns. However, Ms. Myrick believed that normalizing the use of apps and identifying aspects that work well can help individuals benefit from such technologies.

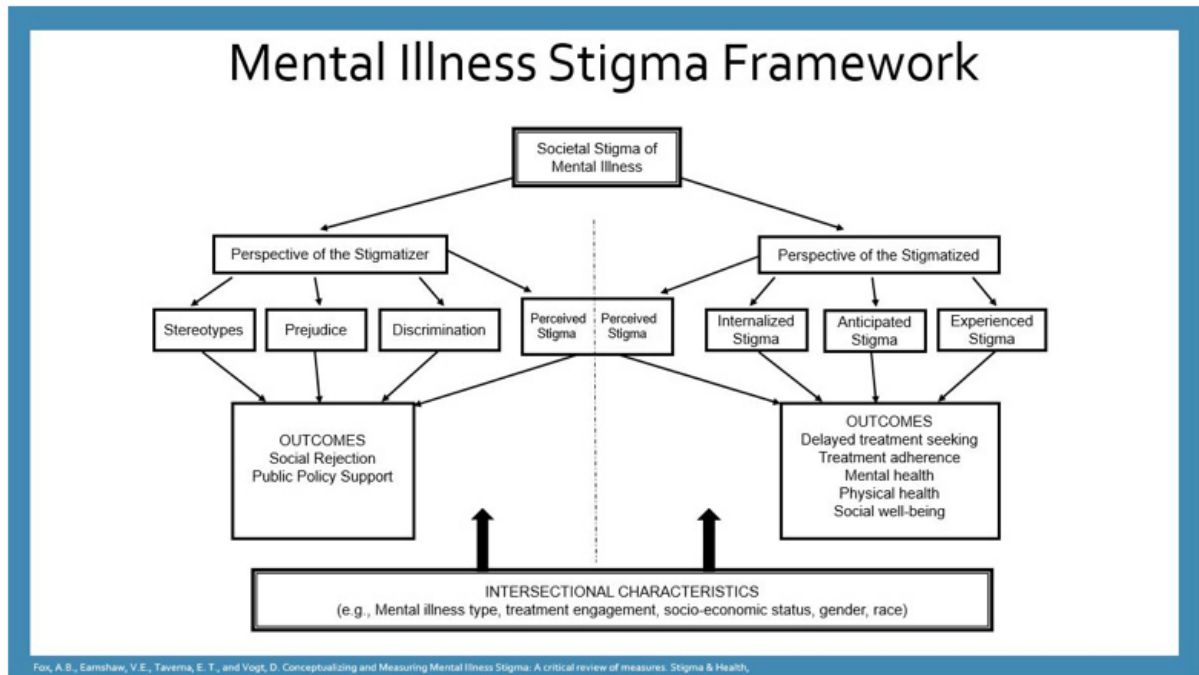
## Defining and Measuring Mental Health Stigma: Keynote Address

Annie B. Fox, Ph.D., gave the keynote address on the second day of the workshop. Her address described how mental health stigma is defined, studied, and measured differently across many disciplines. The presentation revealed that there are more than 400 measures in existence, with the majority of these created for a specific study. Numerous frameworks for understanding mental illness stigma have been introduced, yet they lack clarity and consistency. This highlights the challenging nature of addressing stigma and interpreting stigma research.

*Numerous frameworks for understanding mental illness stigma have been introduced, yet they lack clarity and consistency.*

To address this issue, the Mental Illness Stigma Framework shown in Figure 2 was presented. **The Mental Illness Stigma Framework aims to understand mechanisms of mental illness stigma relevant to two primary areas: 1) how the stigma of mental illness is perceived and experienced by the stigmatizer (one who stigmatizes) ; and 2) how the stigma of mental illness is perceived and experienced by the stigmatized (a person described or regarded as worthy of disgrace or great disapproval).** The framework captures how stigma is perceived from both perspectives. It also depicts how other stigma mechanisms (perceived stereotypes, perceived prejudice, perceived discrimination, internalized stigma, anticipated stigma, and experienced stigma) are related, as well as their impact on various outcomes. Intersectional characteristics, such as race, gender, socioeconomic status, mental illness type, and treatment engagement, affect all concepts in the framework.

**Figure 2.** Mental Illness Stigma Framework



The presentation also included a short list of the most popular scales used to measure the key stigma mechanisms shown in **Figure 3**. Although the review of the measures only focused on those relating to mental illness stigma, it was mentioned that there were several measures that examine the stigma of seeking treatment (i.e., treatment seeking stigma).

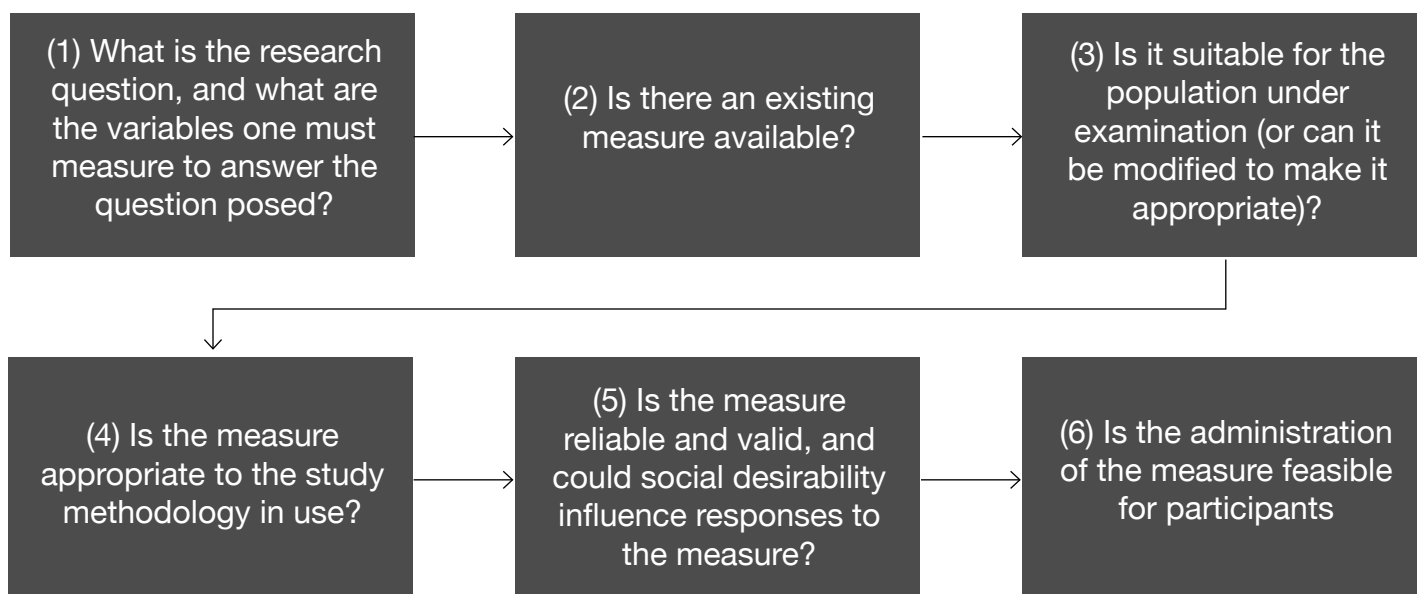
**Figure 3.** Popular Scales to Measure Key Stigma Mechanisms

Perceived Stereotypes	Perceived Prejudice	Perceived Discrimination	Perceived Stigma
<ul style="list-style-type: none"> <li>Internalized Stigma of Mental Illness Scale (ISMI; Boyd, Ritscher et al., 2003)</li> <li>Attribution Questionnaire (AQ; Corrigan et al., 2001)</li> <li>Depression Stigma Scale (DSS; Griffiths et al, 2004)</li> <li>Community Attitudes Toward the Mentally Ill (CAMI; Taylor &amp; Dear, 1981)</li> </ul>	<ul style="list-style-type: none"> <li>AQ</li> <li>CAMI</li> <li>Prejudice Against People with Mental Illness Scale (PPMI; Kenny et al., 2018)</li> </ul>	<ul style="list-style-type: none"> <li>Social Distance Scale (Bogardus, 1933)</li> </ul>	<ul style="list-style-type: none"> <li>Perceived Devaluation and Discrimination Scale (PDD; Link et al., 1987)</li> <li>DSS</li> </ul>
Internalized Stigma	Anticipated Stigma	Experienced Stigma	
<ul style="list-style-type: none"> <li>ISMI</li> <li>Self-stigma of Mental Illness Scale (SSMI; Corrigan et al., 2006)</li> </ul>	<ul style="list-style-type: none"> <li>Social Impact Scale (SIS; Fife &amp; Wright, 2000)</li> <li>Consumer Experiences of Stigma Questionnaire (CESQ; Wahl, 1999)</li> <li>Questionnaire on Anticipated Discrimination (QUAD; Gabbidon et al, 2013)</li> </ul>	<ul style="list-style-type: none"> <li>ISMI</li> <li>CESQ</li> <li>Rejection Experiences (Link, 1997)</li> <li>SIS</li> </ul>	

## Bringing It All Together

Dawne Vogt, Ph.D., facilitated a discussion with Taskforce members to identify and prioritize which mental health stigma measures to use for the Help@Hand evaluation. The discussion began with an orientation on guiding questions developed by Bruce Link (see **figure 4**) to consider when selecting measures. **Figure 4** illustrates the guiding questions. The discussion also referenced learnings from the different sessions presented earlier in the workshop.

**Figure 4.** Six Questions to Guide Measure Selection



Link, B. G., Yang, L. H., Phelan, J. C., & Collins, P. Y. (2004). Measuring Mental Illness Stigma. *Schizophrenia Bulletin*, 30(3), 511–541. <https://doi.org/10.1093/oxfordjournals.schbul.a007098>

Taskforce members were guided to remember the importance of including measures of domains that are likely to be sensitive to and exhibit change over the course of the Help@Hand project. For example, stigma experience, or the extent to which one is deeply discredited and/or experiences discrimination because of one’s mental health status, is critically important, but it may not be reduced through the use of a meditation app, for example.

Additionally, the importance of standardizing the measures across Help@Hand Counties/Cities, populations, and apps was emphasized in the discussion. However, this viewpoint was counterbalanced by a need to be sensitive to specific contexts and target audiences.

Some Taskforce members explained how internalized stigma has a major impact in a person seeking treatment. It was noted that people who feel empowered and have hope may still seek treatment despite anticipating stigma from seeking treatment. Hope and positivity were considered a protective factor. Several Taskforce members also commented on the importance of surveying people about their sense of empowerment and acceptance, instead of focusing on deficits and lack of acceptance. Moreover, Taskforce members thought it would be interesting to compare how treatment seeking stigma for people with lived experience compared to the general population.



*Workshop attendees and members of the Help@Hand evaluation team.*

Following extensive discussions **consensus was reached that the Help@Hand evaluation should include the following mental health stigma dimensions: 1) internalized stigma (particularly alienation and social withdrawal related to internalized stigma); 2) resilience; and 3) mental health treatment stigma. Public and perceived stigma measures were also considered, but given lower priority.** The meeting concluded with a clear agenda to move forward in two specific ways: 1) selecting proposed instruments and 2) examining the impact of labeling.

## Post-workshop: From Stigma Dimensions to Stigma Measures

The tasks remaining after the workshop involved selection of specific scales, sub-scales, and items from validated mental health stigma measures in the literature. To capture Internalized Stigma, the subscale of Alienation and Social Withdrawal from the Internalized Stigma of Mental Illness (ISMI) measure was unanimously agreed upon during the workshop. Three measures for resilience (Stigma Resistance from the ISMI; Recovery Assessment Scale – Revised; and the Connor-Davidson Resilience Scale) were discussed as possible candidates during the workshop, but no consensus was reached. The third construct of Mental Health Treatment Stigma was not examined during the workshop. As such, additional research on existing scales for mental health treatment stigma was conducted in order to present the best options for scales/subscales to attendees in a follow-up call. Public/Perceived Stigma was considered, but judged to have lower priority.

### Process to Reach Consensus

In order to reach consensus on the scales and subscales to use, Taskforce members were asked to participate in a modified Delphi Method process. The Delphi process was conducted between November 2019 and March 2020.

#### The Delphi Method

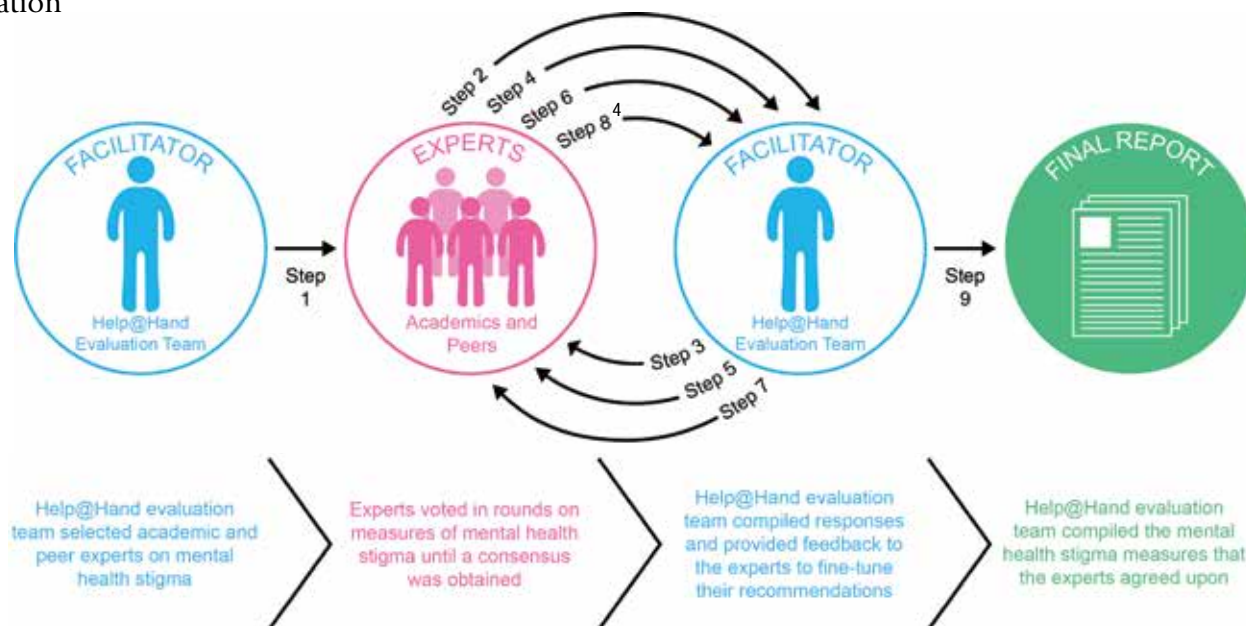
The Delphi method was developed by the RAND Corporation in the 1950s and continues to be used successfully in many fields to this day (Landeta, 2006). The method involves asking a group of experts to provide feedback on a topic using an anonymous questionnaire. The experts subsequently receive feedback in the form of a summary report of the “group’s response” to the questionnaire, and the process is repeated. The Delphi method allows for a discussion without the bias of personalities. Every voter’s voice is heard and the weight of each voter’s argument is an equal factor in the decision process.

#### Modifying the Delphi Method

Figure 5 illustrates the process used to select mental health stigma measures for the Help@Hand evaluation. Taskforce members were asked to rank the stigma measure questions that they viewed as most appropriate for each stigma domain and were offered the opportunity to explain their reasoning. The results were summarized and sent back to the Taskforce members. The process was repeated until consensus was reached, which took four rounds as described in the next section. Due to scheduling, the process was slightly modified to include a telephone meeting for Taskforce members to discuss voting options, deviating from the anonymous voting procedure of the traditional Delphi Method.



**Figure 5.** The Modified Delphi Process Used to Select Mental Health Stigma Measures for the Help@Hand Evaluation



## Rounds of Modified Delphi Process

**Figure 6.** Votes for Each Round of the Modified Delphi Process

DOMAIN	SCALE	SUBSCALE	# OF ITEMS	ROUND 1 # of votes	ROUND 2 # of votes	ROUND 3 # of votes	ROUND 4 # of votes	
Internalized Stigma	ISMI	Alienation	6	6	6	n/a	n/a	Selected in Round 2
		Social Withdrawal	6	6	6	n/a	n/a	
Resilience	ISMI	Stigma Resistance	5	4	4	1	n/a	Eliminated in Round 3
	RAS-R	Personal Confidence and Hope	9	1	1	n/a	n/a	Eliminated in Round 2
		Goal and Success Oriented	5	2	2	n/a	n/a	Eliminated in Round 2
		Reliance on Others	4	0	n/a	n/a	n/a	Eliminated in Round 1
		Not Dominated by Symptoms	3	5	5	3	8	Selected in Round 4
	CD-RISC	n/a	10	4	4	4	1	Eliminated in Round 4
Mental Health Treatment Stigma	ATSPPH-SF	Openness to Seeking Treatment for Emotional Problems	5	2	2	n/a	n/a	Eliminated in Round 2
		Value and Need in Seeking Treatment	5	3	3	n/a	n/a	
	Modified Hoge Scale	Stigma	6	0	n/a	n/a	n/a	Eliminated in Round 1
		Barriers	5	0	n/a	n/a	n/a	
	ADSP	n/a	16	0	0	n/a	n/a	Eliminated in Round 2
SSOSH	n/a	10	5	5	n/a	n/a	Selected in Round 2	

<sup>4</sup> Towards the end of the process, there was consensus for all measures except one. The evaluation team thought the group would benefit from an in-person discussion. As such, they modified the Delphi Method and convened the group in a Zoom meeting to discuss the remaining measure. After a short discussion, it was revealed that there was a misunderstanding on the measure and a consensus was quickly reached.

## Round 1

Round 1 began shortly after the workshop. The Taskforce was presented a total of seven scales made up of 12 subscales and 98 items relating to the three domains of mental health stigma. They were asked to identify and vote for up to 20 items that they considered as “must have” items in the survey for the Help@Hand evaluation. They were given an option to choose up to 10 additional items that might be “nice to have” if the survey had space for more items. **Figure 6** shows the number of votes for items considered “must have” or “nice to have” in Round 1.

Of the seven scales and 12 subscales, one scale (Modified Hoge) and an additional subscale (RAS-R: Reliance on Others) were eliminated because at least two voters did not select 30% of the items in those scales. Thus, only six scales were considered and voted on in Round 2. Of these scales, three had subscales. There were a total of nine subscales considered in Round 2.

## Round 2

During Round 2, the Taskforce was asked to select and vote on entire scales/subscales that remained after Round 1. They could not vote for part of scales/subscales. The total of items in the scales/subscales considered as “must have” or “nice to have” for the survey could not be more than 30 items total. Taskforce members also could anonymously offer explanations for why they felt a scale/subscale should be included or excluded on the final survey. **Figure 6** shows the number of votes for items considered “must have” or “nice to have” in Round 2.

The ATSPPH-SF and ADSP scales were eliminated since less than 40% of the Taskforce voted on these scales as either “must have” or “nice to have” items. Two additional subscales (RAS-R: Personal Confidence and Hope; RAS-R: Goal and Success Oriented) were also eliminated. There was agreement among Taskforce members that the ISMI Alienation and Social Withdrawal should measure internalized stigma in the Help@Hand evaluation survey. There was also agreement that the SSOSH should measure mental health treatment stigma. However, consensus was not reached on which subscales should measure resilience. Thus, a third round was needed.

## Round 3

For Round 3, Taskforce members were limited to selecting only one of the three subscales. **Figure 6** shows the votes for Round 3. The ISMI Stigma Resistance subscale received the fewest votes and was eliminated. However, it was not clear which of the remaining two subscales should be used to measure resilience. Thus, a fourth round was conducted.

## Round 4

Before voting in Round 4, Taskforce members were invited to participate in a follow-up call in order to discuss the two remaining subscales. Eight Taskforce members attended the call and shared the following comments on the subscales:

- RAS-R: Not Dominated by Symptoms and Willingness to Ask for Help
  - Items provided concrete examples that can be easy to understand
  - Items can apply to anyone regardless of where they are in their mental health treatment stage
  - Using two subscales allow measurement of two dimensions
- CD-RISC
  - Survey-takers can have a sense of hope when reading and answering the items given how they are worded
  - Items were worded in a way that resilience was measured in a broad sense. It could go beyond mental health and include physical health

The Taskforce was then asked to select the subscale that they would recommend to measure resilience in the Help@Hand evaluation survey. The result was a strong preference to use the RAS-R Not Dominated by Symptoms and Willingness to Ask for Help subscales, which had 8 of the 9 votes.

# Proposed Measurement Model

Figure 7 depicts all the measures and questions considered. Those boxes outlined in purple are the ones chosen by consensus as the final survey measures. The task force’s recommended measures included:

- Internalized Stigma of Mental Illness (ISMI), which measures internalized stigma via 12 questions related to alienation and social withdrawal;
- Recovery Assessment Scale (RAS-R), which explores several aspects of an individual’s resilience. The task force recommended using only the questions on willingness to ask for help and questions about not allowing symptoms to dominate; and
- Self-Stigma of Seeking Help (SSOSH), a 10-question survey looks at mental health treatment stigma.

Figure 7. Mental Health Stigma Measures Considered and Selected for the Help@Hand Evaluation

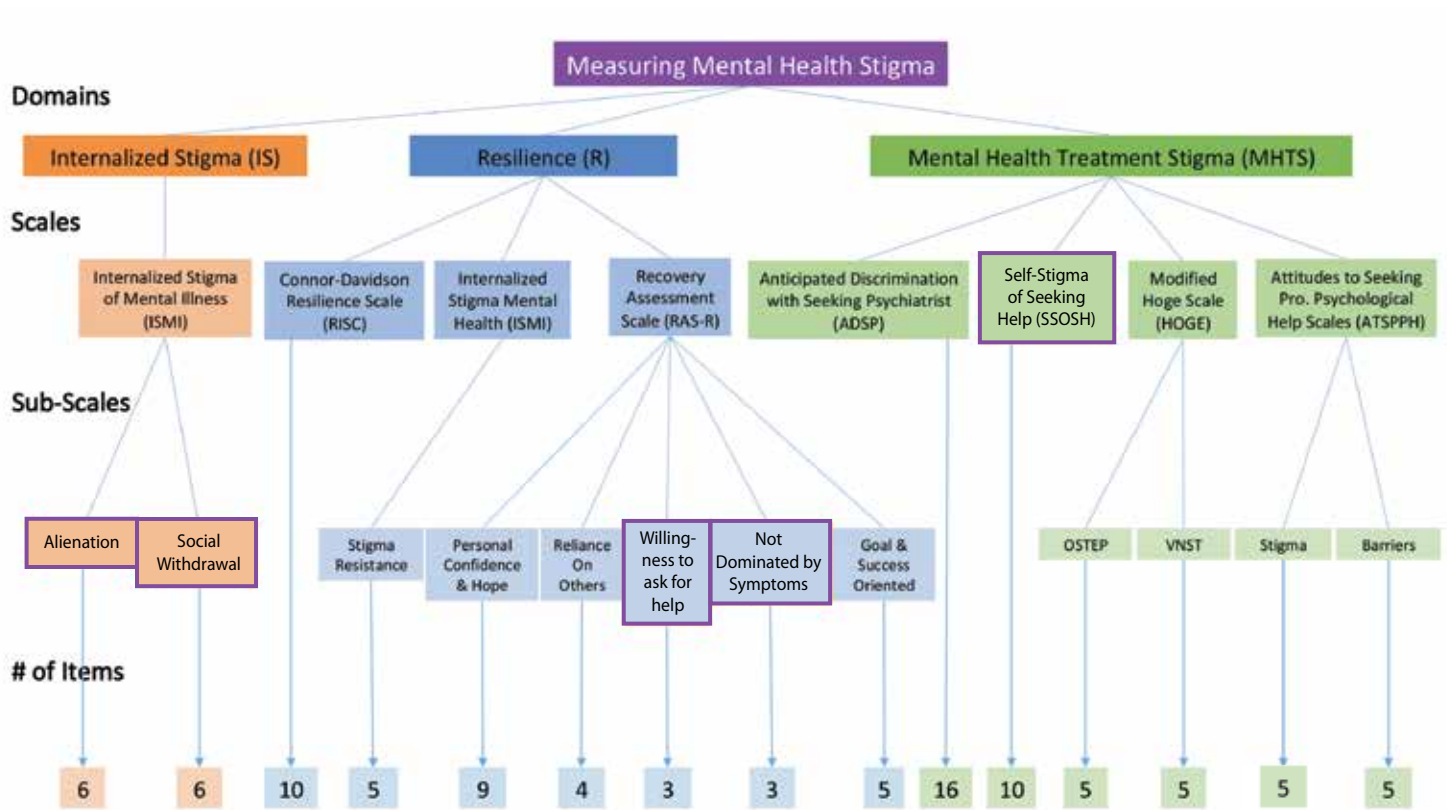


Figure 8 details the recommended measures and questions. Twenty-eight questions were selected and will be incorporated in the Help@Hand evaluation.

Figure 8. Mental Health Stigma Measures Selected for the Help@Hand Evaluation

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

## Learnings and Recommendations

A Peer and Academic-partnered approach was facilitated to select appropriate instruments to measure mental health stigma in the Help@Hand evaluation. Learnings and recommendations that may inform future related efforts include:

- **Learning:** No single instrument can capture the complexity and nuance of mental health stigma.  
*Recommendation:* When selecting instrument(s) consider the context of the measurement: the nature, the scope, and use case around the inquiry. Consider (1) Will measurement occur at one time or repeatedly, and is the proposed instrument sensitive to change? (2) What is the target audience, and what constructs are relevant? (3) What is the technology and use-case for implementation, and how might that influence change in mental health stigma?
- **Learning:** The selection of the proposed instruments was guided by the belief that it was important to prioritize a measurement strategy that was specifically relevant to the Help@Hand project.  
*Recommendation:* Other projects and efforts may adopt a different set of instruments to measure the same or similar constructs.
- **Learning:** Although there are a number of recommended measures to use, the experts focused on balancing psychometric properties of strong measurement with practical considerations.  
*Recommendation:* When selecting appropriate measures, consider the balance of psychometric strength with feasibility around time, availability of funds, and necessary level of precision.
- **Learning:** A community-based selection process that incorporates multiple stakeholder perspectives, including those of Peers, takes time, but is critical in selecting appropriate mental health stigma measures.  
*Recommendation:* Build time into the selection process for including non-academic experts and other stakeholders.
- **Learning:** Using a community process to discuss mental health stigma formed important collaborations and working relationships based on trust and shared decision-making that extended beyond this work.  
*Recommendation:* A psychologically safe environment is one where everyone in attendance feels accepted and respected. This environment can be created by including everyone from the very start of the meeting and establishing that everyone's ideas and contributions are important. Furthermore, consider incorporating diverse learning and sharing models (e.g., group presentation, artistic expression, dyadic lecture, group work, shared meals with topical discussion, physical activity) to bring people together to facilitate meaningful interaction based in mutual respect, knowledge and trust.
- **Learning:** Educating experts on the experience of individuals with lived experience and/or family member experience was necessary to establish common understanding of stigma.  
*Recommendation:* Ensure that the ideas of every single person in the room are heard. Recognize that each stakeholder brings their expertise. Working with a strong group facilitator is important.
- **Learning:** Learning about existing instruments from the experts was required to ensure that the selection and decision-making process aligned with psychometric science.  
*Recommendation:* Consider carefully the qualifications of the invited experts and match to the project needs. For example, there are important disciplinary differences and expectations around measurement that might be important to consider in a project.
- **Learning:** Utilizing a Delphi process to select mental health stigma measures took time, but allowed all academic and peer experts to voice their opinions freely. Maintaining interest and enthusiasm contributes to active participation throughout the process.  
*Recommendation:* Measuring the Help@Hand project's impact on mental health stigma across Counties/Cities will be strengthened if each Help@Hand County/City uses the recommended instruments in a similar and consistent fashion.

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## Appendix A: Bios of Workshop Speakers and Attendees

### **Jennifer E. Boyd, PhD**



Jennifer E. Boyd is the Psychology Director at the San Francisco VA Health Care System, as well as a Professor of Clinical Psychiatry at the University of California, San Francisco. Dr. Boyd was educated at Stanford University, the University of Maryland, Georgetown University, and Columbia University. Her most recent research focuses on the internalized stigma of severe mental illness and mental health providers with a lived experience of mental illness. In her clinical, teaching, and advocacy work, Dr. Boyd supports the recovery model of psychosocial rehabilitation. She has received awards from the American Psychological Association including the Division 18 award for Outstanding Contributions in Psychosocial Rehabilitation, the Michael S. Neale award for service to people with serious mental illness, and a Presidential Citation for her work on stigma, as well as the inaugural Jennifer E. Boyd

Award from the VA Mental Health Lived Experience Community of Practice.

### **James L. Clement, MBA, PE**

James (Jim) L. Clement recently retired from a career with NASA which spanned the entire 30-year Space Shuttle Program. He used his experience as an aerospace engineer and Air Force pilot to develop and document many of the first-of-a-kind cockpit displays and procedures for the Space Shuttle. These displays were still in use when the last Shuttle flew in 2011. As a certified Mission Control Center flight controller, Jim served on console in the storied NASA mission control room for many Space Shuttle missions, including the ill-fated Challenger mission. His peer-reviewed publications focus on international space operations. Jim advanced through the ranks at NASA into senior management and later in his career transferred to the NASA Ames Research Center in Mountain View, California where he served as a research directorate executive until his retirement. Jim is also a decorated combat pilot who retired as a Colonel after a 30-year active duty and reserve career in the Air Force. In his personal life, he has been the single father of two sons, one of whom is now a single father of a teenage son. Jim has mentored young people throughout his career and has received mentoring awards from NASA and the Air Force. Jim continues his love of promoting science and technology to others through speaking, writing, and photography. He has spoken at Rotary clubs, the San Francisco Public Library, retirement centers and at several Stamp Out Stigma events regarding his personal experiences and lessons learned.

### **Patrick Corrigan, PsyD**

Patrick (Pat) Corrigan is a Distinguished Professor of Psychology at the Illinois Institute of Technology. Previously, Pat was Professor of Psychiatry at the University of Chicago where he directed its Center on Psychiatric Rehabilitation. Pat's research examines psychiatric disability and the impact of stigma on recovery and rehabilitation. His work has been continuously supported by the National Institutes of Health since 2001. Pat has written more than 400 peer-reviewed articles, and is editor emeritus of the American Journal of Psychiatric Rehabilitation. He is editor of a new journal published by the American Psychological Association, Stigma and Health and has authored seventeen books.

### **Valerie Earnshaw, PhD**



Valerie Earnshaw is a social psychologist who studies how stigma leads to health inequities among people living with a range of socially devalued characteristics and identities. She has contributed to theories that delineate ways in which stigma is experienced by individuals living with and without socially devalued characteristics. Valerie has also contributed to stigma measurement, including by developing and evaluating measures of chronic illness stigma, HIV stigma, and substance use stigma. She has worked with colleagues to test the generalizability of stigma scales in new populations and contexts. Valerie is an Assistant Professor of Human Development and Family Sciences at the University of Delaware.

### **Annie B. Fox, PhD**



Annie B. Fox is an Assistant Professor of Quantitative Methods at the MGH Institute of Health Professions in Boston, MA. She received her Ph.D. in Social Psychology with a certificate in Quantitative Methods from the University of Connecticut in 2011. Prior to joining the IHP, she was a post-doctoral research associate in the Women's Health Sciences Division of the National Center for PTSD. Annie's research examines the conceptualization, measurement, and consequences of mental illness stigma. She and her colleagues developed the Mental Illness Stigma Framework, a conceptual framework that identifies the key components of stigma from both the perspective of the stigmatized and the perspective of the stigmatizer, and provides operational definitions that can be used by researchers to ensure that terms are used consistently throughout the literature. With her colleagues at the National

Center for PTSD, she has published several studies examining how mental illness stigma impacts the lives of post-9/11 US veterans, including their use of mental health treatment and their overall work functioning. Annie's methodological interests involve the application of advanced statistical techniques to the analysis of longitudinal data. She currently serves as a statistical consultant on several NIH funded studies, teaches graduate courses in statistics, and serves as the primary quantitative methodologist for faculty and graduate students at the MGH Institute of Health Professions. Her research has been published in national and international journals, including *Social Psychiatry and Psychiatric Epidemiology*, *Clinical Psychological Science*, *Journal of Affective Disorders*, *Journal of Traumatic Stress*, *Psychological Trauma: Theory, Research, Practice and Policy*, *Psychology of Women Quarterly*, and *Stigma & Health*.

### **Alyssa Ghirardelli, MPH, RD**



Alyssa Ghirardelli is a Senior Research Scientist with over 20 years of experience in public health and behavioral research. With her current position at the National Opinion Research Center (NORC) at the University of Chicago, she is based in the California office which focuses on health communication and behavioral health research. Alyssa has been with NORC since 2013 and has experience with formative research for program and campaign development including focus groups, key informant interviews and other qualitative methodologies. She also has experience with quantitative evaluation, instrument design including cognitive testing, segmentation, management of large surveillance surveys through multiple modes as well as developing and conducting trainings for field survey administration. Her content areas of expertise include, maternal and child health, mental health stigma reduction, health equity and disparities, and obesity prevention. Previously, Alyssa served as a Research Scientist and Principal Investigator with the Network for a Healthy California where she led state-wide research and evaluation projects including mass media campaign evaluation and food environment research linking with the California Tobacco Control Program retail research studies. Her work has included projects with the Robert Wood Johnson Foundation, the California Department of Public Health, the California Department of Health Care Services Medical Director's Office, the California Mental Health Services Authority, First Five California, the State of North Carolina Physical Activity and Nutrition Branch, the National Institute of Environmental Health Sciences and UNC-Chapel Hill Departments of Nutrition, Epidemiology, Health Behavior Health Education, Medicine, and Dental Ecology. Alyssa is also a passionate parent of two boys. She likes to ski, ride waves, and bike on the weekends and sometimes makes wine in her basement. In a past life, she was a modern dance choreographer and performer creating nine original full production dance works and dancing in over 35 pieces by other dance makers.

### **Shannon McCleerey-Hooper**



Shannon McCleerey-Hooper is the Consumer Peer Program Manager at Riverside University Health System (RUHS)- Behavioral Health, Consumer Affairs. Shannon came to RUHS-Behavioral Health after working as a school teacher in Beaumont, CA. She began her career with the County as a Peer Support Specialist in the Banning Adult Outpatient Clinic and began developing, writing and presenting training materials for Peer Support Specialists shortly thereafter. Upon promotion to Program Administrator in 2013, her consumer peer staff consisted of 82 members. Her program has grown to roughly 160 full time, fully benefited and union represented Consumer Peer Support Specialists and 17 Senior-level Peer Support Specialists that work full time for the County Behavioral Health System. As a consumer of mental health services, a family member and a parent of two children with behavioral health challenges, she works to reduce stigma for those who live with a diagnosis. Her passion is centered on training and support for those who work professionally as peer providers in public behavioral health and substance use treatment service systems. Her Consumer Affairs division of Behavioral Health educates clinical staff, who work with peer providers on treatment teams. She received her Bachelor of Arts Degree from California State University, Fullerton in 1989.

She has mentored Senior Peer Support Specialists (leadership-level peer support mentors) in public speaking, authored educational curricula and facilitated workshops on recovery model concepts and service provision.

She has presented at conferences internationally, including CASRA (California Association of Rehabilitation Agencies), "Pathways to Client-Centered Care" at the University of Southern California, Behavioral Health Symposium at Redlands University, NAMI (National Alliance for Mental Illness), and International Association of Peer Support Specialists Conference and, most recently at the Orygen Youth Mental Health Symposium in Melbourne Australia. She has provided recovery model training to MFT students at Loma Linda University, Cal Baptist University and University of California, Riverside. She has received awards in Riverside County "The Modeling Recovery" Senior Peer Support Specialist of the year for 2013 and was awarded Mentor of the Year in 2010, 2012 & 2013. In 2012, she published an article in Paradigm Magazine, titled "Building A Legacy" on Peer Support Programs in Riverside County. Most recently, she was recognized by the California State Council on Mentally Ill Offenders (COMIO), which changed their name because of their interactions with her team of peer providers who advocated for their organization to remove the stigmatizing labels in their name. Now called Council on Criminal Justice and Behavioral Health CCJBH) as a "Promising Program" with regard to her Peer Navigation Program that includes a toll free number that is manned by Peer Support Specialists full time to provide real time warm hand-offs to resource agency partners for individuals leaving incarceration or psychiatric hospitals.

### **Keris Jän Myrick, MS, MBA**



Keris Jän Myrick is currently the Chief, Peer Services for the Los Angeles County Department of Mental Health. Keris was formerly the Director of the Office of Consumer Affairs for the Center for Mental Health Services (CMHS) of the United States Health and Human Services' Substance Abuse and Mental Health Services Administration (SAMHSA). Keris is a leading mental health advocate and executive, known for her innovative and inclusive approach to mental health reform and the public disclosure of her personal story. She has over 15 years of experience in mental health services innovations, transformation, and peer workforce development. Keris was previously President and CEO of Project Return Peer Support Network, a Los Angeles-based, peer-run nonprofit, the President of National Alliance on Mental Illness (NAMI), and served as a consultant to the American Psychiatric Association (APA) Office of Minority and National Affairs (OMNA).

Keris is featured in the CalMHSA documentary A New State of Mind: Ending the Stigma of Mental Illness and her personal story was featured in the New York Times series: Lives Restored, which told the personal narratives of several professionals living with mental health issues. With her unique combination of executive skills, personal lived experience in the mental health system, and an author of several peer reviewed journal articles, Keris is an in-demand national trainer and keynote speaker. She is known for her collaborative style and innovative "whole person" approach to mental health care.

Keris has a Master of Science degree in organizational psychology from the California School of Professional Psychology of Alliant International University. Her Master of Business Administration degree is from Case Western University's Weatherhead School of Management.

## **Pamela Norton**



Pamela Norton is a Senior Peer Support Specialist for the Tech Suite Innovations Project for Riverside University Health System-Behavioral Health. She is a mother with two adult children; a daughter to a mother (living), a dad (living), and a biological father (deceased); a sister to an older brother, a younger brother, a younger sister; and a wife. She is a person living in recovery for mental health and substance use challenges. She has worked in the field of behavioral health in some capacity for the past 16 years.

Stigma impacted her life. Stigma prevented some of her family members from seeking services in the past. Stigma created a lack of education, understanding and acceptance in seeking services. Stigma prevented openness and opportunities for conversation and validation, keeping mental health in the realm of family secrets. Stigma reinforced shame. Pamela feels strongly about ending stigma.

## **Vanessa Ramos**



Vanessa Ramos is a bi-lingual Project Manager at the Department of Behavioral Wellness for the County of Santa Barbara. In this role, she is responsible for overseeing all aspects of implementation for the Help@Hand Project funded by the Mental Health Services Act. Previously, Vanessa served as a featured blogger with Hilton Worldwide's Award Winning @HiltonSuggests Twitter Travel Blog. She also shared her expertise in areas of International Corporate Human Resources with a focus on Labor Law at U-Haul International. In her personal life, she enjoys a life of recovery and hope on the coast with her daughter, Esther, and her partner, Aaron. She enjoys the arts, gardening, and encouraging her community to see with their own eyes and feel with their own hearts as spoken by the great Albert Einstein.

## **Kelechi Ubozoh**



Kelechi Ubozoh is a nationally recognized Nigerian-American writer and mental health advocate. Her story of recovery was featured in O, The Oprah Magazine, CBS This Morning with Gayle King, Good Morning America, and ABC Channel 7 News. Kelechi was also featured in the SAMSHA Voice Award-Winning documentary, The S Word, which follow the lives of suicide attempt survivors to end the stigma and silence around suicide. Previously, Kelechi supervised stigma discrimination reduction programs and led communication operations at a mental health non-profit organization, PEERS, including a mental health stigma reduction research program for Chinese mental health consumers where she partnered with Dr. Larry Yang and Columbia University. She also worked with Mental Health Association of San Francisco- MHA-SF on a statewide project, where she applied evidence-based research from working with Dr. Patrick Corrigan to train speakers' bureau on how to share targeted mental health recovery stories across 41 California counties. Her first book with co-editor LD Green, "We've Been

Too Patient: Voices from Radical Mental Health," was released this summer from North Atlantic Books and Penguin Random House. We've Been Too Patient is a collection of diverse stories of radical healing and consider the recent movement towards reform in the mental health field, including the consumer movement, peer support, and trauma-informed care. She currently works at CalMHSA as the Tech Suite Peer and Community Engagement Manger.

### **Dawne Vogt, PhD**



Dawne Vogt is a Research Health Scientist in the Women's Health Sciences Division, National Center for Posttraumatic Stress Disorder (PTSD) at VA Boston Healthcare System, and Associate Professor of Psychiatry at Boston University School of Medicine. She has published extensively in the veteran literature (h index = 45), received support for her research from VA, DoD, NIH, foundations, and other private industry, and given over 60 invited talks and conference symposia/Taskforce presentations. Her program of study focuses on the social determinants of military veterans' mental health, health-care use, and broader well-being. Within this broader topic, she pursued research aimed at promoting understanding of how societal stigma about mental illness and mental health treatment impacts military veterans' treatment seeking. Notable accomplishments in this regard include developing

and validating measures that can be used to assess different aspects of treatment-seeking stigma, publishing a highly cited review of the literature on how mental health stigma affects the treatment seeking of current and former service members, and documenting mechanisms underlying the association between different aspects of stigma and military veterans' treatment seeking in a series of empirical studies.

### **Samantha Spangler, PhD**

Dr. Samantha Spangler is Research and Evaluation Director for the California Institute for Behavioral Health Solutions. Dr. Spangler has 15 years of experience in research, analytics, and evaluation, including work with academic, government, corporate, and non-profit organizations. Dr. Spangler completed a fellowship in interdisciplinary autism research at the UC Davis MIND Institute and has previously worked as a consultant to state and local governments nationwide to provide planning, implementation, and evaluation support for health and human services initiatives. She provides expertise in research and evaluation design and execution and works with organizations to understand how they can continuously improve the quality of their services and outcomes for the populations they serve.

## Appendix B: Glossary of Terms

Stigma Concept	Definition	Examples/Sample item stems
Alienation	Feeling set apart from others	<ul style="list-style-type: none"> <li>• I feel out of place in the world because I have a mental illness</li> <li>• Having a mental illness has spoiled my life</li> </ul>
Anticipated Stigma	Expectations of being the target of stereotypes, prejudice, and discrimination from others in the future	<ul style="list-style-type: none"> <li>• If people find out about my mental illness, they will think I am weak.</li> <li>• I worry that I may lose my job if my boss finds out I have a mental illness</li> </ul>
Discrimination	Unfair or unjust treatment of People with Mental Illness (PWMI)	<ul style="list-style-type: none"> <li>• I would not marry someone with mental illness.</li> <li>• I would not hire someone with mental illness.</li> <li>• A person with mental illness should be locked up in a mental hospital.</li> </ul>
Discrimination Experience	Perceived exposure to discrimination	<ul style="list-style-type: none"> <li>• People discriminate against me because I have a mental illness</li> <li>• Others think that I can't achieve much in life because I have a mental illness</li> <li>• People ignore me or take me less seriously just because I have a mental illness</li> </ul>
Experienced Stigma	Experiences of stereotypes, prejudice, and/or discrimination from others in the past or present	<ul style="list-style-type: none"> <li>• People often patronize me, or treat me like a child, just because I have a mental illness</li> <li>• People discriminate against me because I have a mental illness</li> <li>• I have been turned down for a job for which I was qualified when it was revealed that I am a MH consumer</li> </ul>
Internalized Stigma	Endorsement of the negative beliefs and feelings attached to the identity, and applying these to the self	<ul style="list-style-type: none"> <li>• I feel out of place in the world because I have a mental illness</li> <li>• Because I have a mental illness, I need others to make decisions for me</li> <li>• I am less of a person because I have a mental illness.</li> </ul>
Perceived Stigma	Items refer to other people's opinions, beliefs, or behaviors	<ul style="list-style-type: none"> <li>• Most people think that having a mental illness is a sign of personal weakness</li> </ul>
Prejudice	Emotions and feelings toward PWMI	<ul style="list-style-type: none"> <li>• I am afraid of people with mental illness.</li> <li>• People with mental illness should be ashamed</li> </ul>
Public Stigma	Stigma that a people have about those with mental illness	<ul style="list-style-type: none"> <li>• People with mental illness experience high levels of prejudice and discrimination</li> </ul>
Resilience	The ability to adapt to difficult situations	<ul style="list-style-type: none"> <li>• Coping with my mental illness is no longer the main focus of my life</li> <li>• I know when to ask for help</li> </ul>
Self-help Stigma	Stigma associated with seeking mental treatment	<ul style="list-style-type: none"> <li>• I would feel inadequate if I went to a therapist for psychological help</li> <li>• I would feel worse about myself if I could not solve my own problems</li> </ul>
Self-Stigma	Stigma a person has about their own mental illness	<ul style="list-style-type: none"> <li>• I am disappointed in myself for having had a mental health problem</li> <li>• I am embarrassed or ashamed that I have had a mental health problem</li> </ul>
Social Withdrawal	Pulling away from contact with others due to concerns about the status of having a mental illness – not directly due to symptoms	<ul style="list-style-type: none"> <li>• I don't talk about myself much because I don't want to burden others with my mental illness</li> <li>• I avoid getting close to people who don't have a mental illness to avoid rejection</li> </ul>

Stigma Concept	Definition	Examples/Sample item stems
Stereotypes	Beliefs about the characteristics and behaviors of PWMI	<ul style="list-style-type: none"> <li>• People with depression are morally weak</li> <li>• Depression is caused by moral failing</li> </ul>
Stereotype Endorsement	Believing stereotypes about mental illness	<ul style="list-style-type: none"> <li>• Stereotypes about the mentally ill apply to me</li> <li>• People can tell that I have a mental illness by the way I look</li> <li>• Mentally ill people shouldn't get married</li> </ul>
Stigma Resistance	Lack of stigma and ability to resist stigma	<ul style="list-style-type: none"> <li>• I feel comfortable being seen in public with an obviously mentally ill person</li> <li>• In general, I am able to live life the way I want to</li> <li>• Living with mental illness has made me a tough survivor</li> </ul>

Fox, A.B., Earnshaw, V.E., Taverna, E.T., and Vogt, D. Conceptualizing and Measuring Mental Illness Stigma: A critical review of measures. *Stigma & Health*.





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Evaluation

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