Measuring Recovery from Substance Use and Mental Disorder

Discussion Brief

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**Why Measuring Recovery is Important**

SAMHSA would like to expand its behavioral health data collections to include measures of recovery from substance use and mental disorder. Measuring recovery is important for several reasons:

1. Currently there is no data collection in the United States that produces national level estimates of the number of persons who are in recovery or who have recovered from a substance use or mental disorder. SAMHSA would like to fill this gap.

2. There is a movement of people who would like to be counted.

3. Recovery is embraced as a national policy goal and is important for measuring policy and program impacts (e.g., Affordable Care Act; Mental Health Parity Act; state and local initiatives). Estimates of the number of people in recovery can facilitate the implementation of performance measures.

4. High quality data are critical to disseminating the message that recovery is attainable and desirable and to reducing stigma. Data are also useful for building political will.

5. Data are needed to promote knowledge development on the recovery process. Much previous work has focused on clinical samples (i.e., measures of treatment effects, generally over relatively short time periods), leaving out the experience of the vast majority of those who meet DSM criteria, but do not go to treatment. Epidemiological studies have largely been cross-sectional.

**Many Definitions of Recovery**

Kenneth Wells said that “Recovery is a broad concept affected by the perspective of the stakeholder and potentially influenced by a range of changes in health insurance, services delivery, organization and policy as well as social policy and community culture programs and their integration across federal, state and local levels.” Accordingly, there are many definition of recovery.

**SAMHSA Definition of Recovery:**

SAMHSA has its own definition of recovery, which states that “Recovery is a process of change through which individuals improve their health and wellbeing, live a self-directed life, and strive to reach their full potential.” Based on this definition, recovery has the following components:

- **Health** is overcoming or managing one's disease(s) or symptoms—for example, abstaining from use of alcohol, illicit drugs, and non-prescribed medications if one has an

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1Workshop presentation by Kenneth Wells, National Academies of Sciences, Engineering, and Medicine, February 24, 2016: See: [http://sites.nationalacademies.org/cs/groups/dbassesite/documents/webpage/dbasse_171055.pdf](http://sites.nationalacademies.org/cs/groups/dbassesite/documents/webpage/dbasse_171055.pdf)
addiction problem—and for everyone in recovery, making informed, healthy choices that support physical and emotional wellbeing.

- **Home** is a stable and safe place to live.
- **Purpose** is to have meaningful daily activities, such as a job, school, volunteerism, family caretaking, or creative endeavors, and the independence, income and resources to participate in society; and
- **Community** to have relationships and social networks that provide support, friendship, love, and hope.

**Other Definitions of Recovery from Substance Use (based on overview by Keith Humphreys²):**

**Remission - Clinical Definition:** Among individuals who had a lifetime substance use disorder, remission is defined as having at least three, but less than 12 months with no symptoms, with the exception of craving. Sustained remission is defined as having at least 12 months with no symptoms, with the exception of craving.

**Association for Medical Education and Research in Substance Abuse** (AMERSA) defines recovery as reaching “a state of physical and psychological health such that abstinence from dependency-producing drugs is complete and comfortable.”

**Betty Ford Consensus Panel** explains recovery as “a voluntarily maintained lifestyle characterized by sobriety, personal health, and citizenship.”

**UK Drug Policy Commission** describes recovery as “a process, characterized by voluntarily maintained control over substance use, leading towards health and well-being and participation in the responsibilities and benefits of society.”

**Connecticut Community for Addiction Recovery** states that “You are in recovery if you say you are.”

**Other Definitions of Recovery from Mental Disorder (based on overview by Kenneth Wells³):**

**World Health Organization** defines mental health as a state of well-being in which every individual realizes his or her own potential, can cope with normal stresses of life, can work productively and fruitfully and is able to make a contribution to her or his community. This definition is very similar to the idea of recovery.

**New Freedom Commission (2003)** report describes recovery as the process in which people (with mental illness) are able to live, work, learn, and participate fully in their communities.

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²Workshop presentation by Keith Humphreys, National Academies of Sciences, Engineering, and Medicine, February 24, 2016. See: [http://sites.nationalacademies.org/cs/groups/dbassesite/documents/webpage/dbasse_171022.pdf](http://sites.nationalacademies.org/cs/groups/dbassesite/documents/webpage/dbasse_171022.pdf)
³See reference in footnote 1 above.
Clinical definitions focus on: symptom remission; return to functioning; being off maintenance medication. 4

Research definitions are numerous, but can include elements such as: 2+ years sustained symptom remission, engagement in role activity (i.e., work, school), living independently, age-appropriate relations. 5

Consumer/Survivor definitions of recovery focus on the process, rather than the outcome and a model of patient-centered approach to treatment. This definition includes strength-based elements such as hope, respect, and empowerment. 6

CONSIDERATIONS FOR DEFINITION OF RECOVERY

To enable SAMHSA to measure recovery there is a need for a definition that: can be operationalized and standardized, is measureable, has face validity, and is clinically meaningful.

Some of the questions and considerations include:

- Whether the definition should capture process, outcomes (symptoms and functioning in various life domains), identity (self-labeling) and strength-based qualities (hope, respect, empowerment, enjoyment of life)?
- Whether abstinence is necessary (e.g., how to classify moderate use and use of medication assisted treatment when measuring recovery)?
- What needs to be measured beyond the characteristics of the individual (e.g. engagement of the family or the community)?
- What measures of doing better should be included, beyond symptoms (e.g. life enjoyment, thriving and function) in relation to a previous time point?
- Is it necessary to establish a threshold that may indicate stability in recovery?
- The definition of recovery in children is less well-established, and because of that there is a stronger focus on understanding social context, risk factors and social determinants, which may require an approach that is different from the one that is used for adults. 7
- Research shows that there is bias in diagnoses by race/ethnicity and it is important to consider the implications for the measurement of recovery. 8

7Wells 2016, see reference in footnote 1 above.
8Wells 2016, see reference in footnote 1 above.
Recovery as a Process: Related Constructs

“Recovery is the experience (a process and a sustained status) through which individuals, families, and communities impacted by severe alcohol and other drug (AOD) problems: utilize internal and external resources to voluntarily resolve these problems, heal the wounds inflicted by AOD-related problems, actively manage their continued vulnerability to such problems, and develop a healthy, productive, and meaningful life.”\(^9\) As a process, recovery is iterative with individuals cycling through the process over the course of years. Some external events that promote recovery may also impede it (for example, life transitions may encourage movement in the direction of health or may temporarily trigger the recurrence of problems).

Process related constructs discussed by Christine Grella include natural recovery, turning point, recovery capital and “maturing out”.\(^10\) Natural recovery is when people in the general population who have a substance use disorder go into remission without any formal intervention. Turning point is an event, experience, or role transition that results in changes in the direction of a pathway or persistent trajectory over the long-term; transitional life events (e.g., marriage, childbirth, employment, incarceration, illness). Recovery capital refers to assets or resources that individuals with substance use problems can use to cope with stressors and sustain recovery; e.g., having access to treatment services and supportive family, friends, and social networks, including 12-step groups. Maturing out is due to life stage, responsibilities, internal and external events (some common ones are criminal justice system external factors, moving out of location with other drug users, alcohol substitution).

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DATA NEEDS

**POPULATION UNIVERSE:** SAMHSA would like to produce national population estimates of recovery from substance use and mental disorder. However, it appears that state level estimates may also be useful to inform block grants and other federal initiatives. In either case, what is needed is a representative population based survey, not a treatment population survey (although a survey of populations that are being treated would also be useful, it would not meet the needs stated by SAMHSA).

A screening approach may be needed to identify a subset of the population from a survey representative of the U.S population. Oversampling of some groups may be needed in order to be able to conduct the types of analyses specified by SAMHSA (e.g., by demographic groups and possibly diagnostic groups). A screen would identify individuals who self-identify as having had a substance use or mental disorder (and potentially “sub threshold” level disorder). Those who screen positive on diagnosis would receive a more detailed set of follow-up questions.

**PERIODICITY AND DESIGN:** Yearly estimates are not necessary and may be too expensive. Some potential options are:

1. Design a new comprehensive survey to be conducted every 3-5 years to provide national (and potentially state level) estimates by population groups of interest and covariates, as well as longitudinal data. One option might be to use the NSDUH frame and decrease the
frequency with which NSDUH is conducted. For example, the NSDUH could be moved to an every other year cycle with the recovery survey administered in “off” years.

2. **Utilize an existing survey** and dedicate smaller yearly samples (e.g., 20-30%) of the ongoing survey with the intent of combining data across several years to provide national (and potentially state level) estimates every 3-5 years. This seems preferable to the first option above because of costs reasons and to diminish the risk that a survey conducted every 5 years could be eliminated.

3. **Develop a longitudinal survey** either as part of a new or an existing survey. In addition to providing national (and potentially state level estimates), this survey would capture trajectories over time and follow outcomes via prospective data. SAMHSA could consider following a subsample of a larger survey over time. This subsample would be drawn from individuals initially screened and deemed to have a substance use or mental health disorder in one of the ongoing population level surveys.

**AGE:** A survey to capture recovery in children would undoubtedly be challenging and needs an approach that is different from that for the adults, because substance use and mental disorders, as well as what “recovery” from these means, is different and less well defined in children. It may make most sense to first determine how to measure recovery in adults while engaging in research to define the concept in children.

**DIMENSIONS OF RECOVERY TO MEASURE**

There are many dimensions of recovery from substance use and mental disorders, and some decisions will need to be made in terms of what SAMHSA wants to capture.

**Identity.** Questions such as “Are you in recovery” or "Did you once have a problem with drugs or alcohol but no longer do?" (Pathways study 2002 & Partnership for Drug Free America 2011 survey) speak to the identity dimension.

**Process & Multidimensional.** One way to describe recovery from substance use is: sobriety and improved quality of life. Recovery is multidimensional and the dimensions that improve can vary over the course of recovery. Because of this, it is not possible to have a measure that consists of one number or score for recovery.

**Recovery capital.** One method for assessing the quality and quantity of recovery capital consists of eight domains: reliance on God and faith; spirituality; recent sobriety; stable income;

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14Laudet 2016, see reference in footnote 13 above.
alcohol/drug-free environment; percent lifetime spent free from the effects of substance use; satisfaction with living situation; amount of education/training.\textsuperscript{15}

**Diagnoses & Remission.** DSM-5 defines full remission from substance use disorders as a sustained period of time (at least 3 months) during which no criteria for substance use disorders are met (the exception is craving, which may be present during remission). In addition, it is possible to be “in recovery” without full remission.

- There are pros and cons of including all diagnoses vs serious mental illness only; symptoms; sub-threshold
- For substance use, it is important to be able to assess periods of abstinence and use.
- It is important to capture trajectories or improvement in co-occurring symptoms and dimensions of recovery (e.g., functioning in various domains, quality of life, etc.).

**Mental Health.** Beyond recovery from mental illness, the concept of flourishing is also important.

**Functioning.** Functioning is important in various life domains, such as the domains that are part of SAMHSA's definition of recovery. In addition, there may be different domains relevant to children.

**Recovery Measures**

Recovery measures vary in type with some focusing more on aspects of care system and care quality. Others focus on characteristics of recovery along the domains that SAMHSA is interested in.

Some measures of recovery from mental disorder to consider are:\textsuperscript{16}

- **Recovery Assessment Scale (RAS)** Used in 222 articles, 77 with psychometric data. The scale has positive associations with related constructs, negative associations with symptoms. The scale has a 20-item version.\textsuperscript{17}

- **Mental Health Recovery Measure (MHRM)** Positively correlated with QOL, negatively correlated with depression. The scale has a 10-item version.\textsuperscript{18}

- **Maryland Assessment of Recovery (MARS)** (SAMSHA domains) Consists of 27 items including recovery process and self-efficacy.\textsuperscript{19}


\textsuperscript{16}Also see workshop presentation by Mark Salzer, National Academies of Sciences, Engineering, and Medicine, February 24, 2016. See: http://sites.nationalacademies.org/cs/groups/dbassesite/documents/webpage/dbasse_171028.pdf.


Liberman and colleagues suggest a 2-year period of functioning within normal limits in the domains of symptomatology, participating in work or school, living independently, and maintaining social relationships.  

**Some measures of recovery from substance use to consider are:**

Alexandre Laudet"superscript 21" said that in 2008 the United Nations’ Treatment Group recommended using the Addiction Severity Index"superscript 22" and the World Health Organization Quality of Life (WHOQOL)"superscript 23" to assess:

- Maintenance of abstinence or reduction in substance dependence;
- Improvement in personal and social functioning;
- Improvement in mental and physical health;
- Reduction in risky behavior that could affect health, and
- Overall improvements in increasing access to livelihoods assets and recovery capital.

The Addiction Severity Index assesses and measures change in addiction severity and includes questions in the domains of: employment; medical; psychiatric; family/social; alcohol and drug use; and legal status.

The World Health organization Quality of Life instrument assesses domains that are highly relevant to recovery, assesses both positive and negative aspects of life, and has objective and subjective ratings. The scale has strong psychometrics, is the public domain, capitalizes on over 20 years of field work, and is cross-culturally validated in 15 centers worldwide. There are published norms for well and ill persons. The scale has 26 items, and it takes 20 minutes to administer by an interviewer or 15 minutes to self-administer.  

**METHODOLOGICAL ISSUES & TRADEOFFS**

There are several methodological issues and tradeoffs that will need to be considered once potential measures are identified. These include:

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20 Liberman and Kopelowicz 2002, see reference in footnote 5 above.
• **Length and mode of administration:** Conducting clinical interviews may be prohibitively expensive. SAMHSA could explore the use of lay interviewers for in-person data collection of an initial diagnostic interview. Subsequent longitudinal data collections could be multi-mode. Web-only administration could lead to bias in the sample and higher rate of incompletes and refusals. An in-person data collection seems most appropriate for getting a representative sample. Regardless of mode of administration, it may be advisable to keep the length of the survey around 1 hour.

• **Languages:** Data collections in English and Spanish seem most realistic and needed based on population growth projections.

• **Costs and feasibility:** These need to be considered over time to decide on whether a new separate survey or add-ons to existing surveys would be best. Add-in to existing surveys will require eliminating some current items from those surveys, to minimize cost and respondent burden, but this approach (with significant changes to the existing design regarding content, follow-up modules, and a potential longitudinal feature) seems most cost effective and feasible. However, note that the amount of data needed to effectively measure recovery is substantial and could result in a survey administration time that exceeds reasonable limits for adding items to existing surveys.

• **Sampling:** An option would be a tiered approach wherein the larger sample gets a screen and a smaller, more targeted sample gets an additional set of items at the same time or later. A longitudinal approach has benefits but also additional challenges related to follow-up and additional costs.

**DESIGN OPTIONS**

1. **RULE OUT:** Adding a very small number of questions to existing surveys like NSDUH. If the items were limited to questions such as "did you have a problem before but no longer do" or "do you identify as being in recovery" this would not yield scientific and valid estimates of recovery prevalence.

2. **IDEAL:** A completely new comprehensive periodic (every 5 years or so) population survey with a longitudinal component (focusing on all 4 areas of interest to SAMHSA for expanding behavioral health data collections: recovery from substance use and mental disorder, specific mental illness diagnoses with functional impairment, serious emotional disturbance in children, and trauma) might be ideal. However, there are obvious questions about costs and the political will to fund such a large undertaking in an ongoing manner.

3. **FEASIBLE:** Revise NSDUH design and content (shorten significantly from its current form) to add measures on recovery, and possibly some of the other behavioral health areas of interest. This might require changes in the sampling approach. Screening questions could be added to identify a subsample for a follow-up module, and these sample members could be contacted at a later time. This may not be adequate to provide data on recovery in children. SAMHSA would have to consider the budget and effort involved. A possibility might be to administer the NSDUH every other year, with a recovery survey administered in the “off” years.
4. **EXPLORE:** Alternative sources of passive data collection could also be considered. For example, there may be patches or other wearable devices that could measure abstinence/sobriety. SAMHSA could explore augmenting the primary data collection with the collection of biological markers (e.g., hair samples), although this approach also has cost implications. It is important to note that biomarkers of substance use alone would not capture other aspects of recovery.

**SUGGESTED NEXT STEPS**

1. **Go or No Go:** SAMHSA will have to decide whether to pursue measuring population level recovery.

2. **Refining definition of recovery:** The definition of recovery will have to be further operationalized, so that it is measureable, valid and clinically relevant. The definition has to be relevant for both substance use and mental disorders. If SAMHSA intends to collect data about recovery in children, further research is needed and a separate definition or different operationalization may be needed for children.

3. **Assess support from key stakeholders:** SAMHSA needs to assess the level of support and interest in the ideal or feasible options described.
   - If ideal or feasible options are doable, consider guidance from stakeholders from: (a) public, government, and scientific experts; (b) develop a reasonable action plan to make final decisions.
   - Obtain buy-in and active ongoing participation from SAMHSA leadership, units and experts.

4. **Need for scientific studies:** There is a need for scientific studies that refine and operationalize recovery and recovery trajectories, how these differ across demographic and clinical groups, and the role that context plays in promoting recovery.