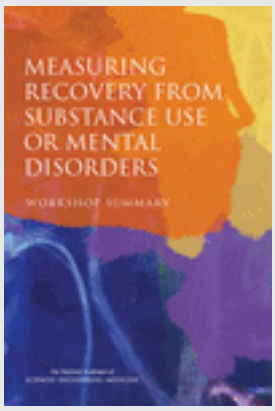

Measuring Recovery from Substance Use or Mental Disorders: Workshop Summary

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Workshop Summary

Krisztina Marton, *Rapporteur*

Committee on National Statistics and
Board on Behavioral, Cognitive, and Sensory Sciences,
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Acknowledgment of Reviewers

This workshop summary has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the Report Review Committee of the National Academies of Sciences, Engineering, and Medicine. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published workshop summary as sound as possible and to ensure that it meets institutional standards for objectivity, evidence, and responsiveness to the charge. The review comments and draft manuscript remain confidential to protect the integrity of the process.

We thank the following individuals for their review of this workshop summary: Christine Grella, Integrated Substance Abuse Programs, University of California, Los Angeles; John F. Kelly, Department of Psychiatry Harvard Medical School and Massachusetts General Hospital Recovery Research Institute and Massachusetts General Hospital Addiction Recovery Management Service; and Mark Salzer, Department of Rehabilitation Sciences and Collaborative on Community Inclusion of Individuals with Psychiatric Disabilities, Temple University.

Although the reviewers listed above provided many constructive comments and suggestions, they were not asked to endorse the content of the summary nor did they see the final draft before its release. The review of this workshop summary was overseen by Susan A. Murphy, Department of Statistics and Institute for Social Research, University of Michigan. Appointed by the National Academies of Sciences, Engineering, and Medicine, she was responsible for making certain that an independent examination of this workshop summary was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this summary rests entirely with the rapporteur and the institution.

Contents

1

Introduction

BACKGROUND

This summary describes the presentations and discussions at the Workshop on Integrating New Measures of Recovery from Substance Use and Mental Disorder into the Substance Abuse and Mental Health Services Administration's (SAMHSA) Data Collection Programs, which was held in Washington, D.C., in February 2016. The workshop was organized as part of an effort to assist SAMHSA and the Office of the Assistant Secretary for Planning and Evaluation (ASPE) of the U.S. Department of Health and Human Services (DHHS) in their responsibilities to expand the collection of behavioral health data in several areas. The workshop was structured to bring together experts in recovery from substance use and mental disorders, and experts in health survey methods to facilitate discussion of measures and mechanisms most promising for expanding SAMHSA's data collections in this area.

The overall effort is being overseen by the Standing Committee on Integrating New Behavioral Health Measures into the Substance Abuse and Mental Health Services Administration's Data Collection Programs.[1] In addition to the topics covered by this workshop, SAMHSA and ASPE are interested in expanding data collection on serious emotional disturbance in children, on specific mental illness diagnoses with functional impairment, and on trauma. Workshops on all four topics are being convened as part of the overall effort.

WORKSHOP FOCUS

Neil Russell (SAMHSA) described his agency's goals in exploring how to best measure and expand SAMHSA's data collection programs to include measures of recovery from substance use or mental disorders. He said that SAMHSA does not currently collect nationally representative data on recovery, but the agency has a working definition of recovery: (see Box 1-1. (See Chapter 3 for a more detailed discussion.) SAMHSA's goal is to measure recovery and to understand the covariates associated with recovery.

Russell pointed out that there are several methodological challenges and questions related to collecting data on recovery. Assuming that there is agreement on the definition of recovery, and questions are added to a general population survey, one decision that needs to be made is which survey respondents should be asked the questions on recovery: all respondents? only those who had an issue in the past year or past month? only those who self-identify as having a substance use disorder or a mental health condition? or only those who self-identify as being in recovery? If not everyone is to be asked all of the questions, are there existing survey

[1]For a description of the overall study, see http://sites.nationalacademies.org/DBASSE/CNSTAT/Behavioral_Health_Measures_Committee/index.htm [March 2016].

instruments that can be used for the screening? One option may be to ask people whether they self-identify as being in recovery, and use that question to determine who gets additional follow-up questions on this topic.

BOX 1-1

SAMHSA'S DEFINITION OF RECOVERY FROM MENTAL DISORDERS OR SUBSTANCE USE DISORDERS

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.

SAMHSA has delineated four major dimensions that support a life in recovery:

Health: 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 addiction problem—and for everyone in recovery, making informed, healthy choices that support physical and emotional wellbeing.

Home: a stable and safe place to live.

Purpose: meaningful daily activities, such as a job, school, volunteerism, family caretaking, or creative endeavors, and the independence, income and resources to participate in society.

Community: relationships and social networks that provide support, friendship, love, and hope.

SOURCE: SAMHSA's working definition: http://blog.samhsa.gov/2012/03/23/defintion-of-recovery-updated [May 2016].

One of the challenges described by Russell is that some of the disorders are episodic or chronic disorders that relapse and remit over time. One question is whether to measure remission from symptoms and symptom relapse, and how these concepts can be operationalized. Another question is whether to include people with subthreshold criteria.

Deciding how to handle cases with co-occurring mental or substance use disorders was another challenge described by Russell. The question is whether these respondents would get different sets of questions for different disorders. More generally, SAMHSA would like to know if there are existing instruments that could be used to measure recovery or if SAMHSA's definition necessitates the development of a new set of questions.

Russell described the parameters that SAMHSA has defined for the data collection on recovery. Using SAMHSA's definition of recovery (see Chapter 3), the goal is to produce estimates of the number of people in the general population who are in recovery or who have recovered from a substance use or mental disorder. SAMHSA also wants to understand the

covariates associated with recovery, including substance use and mental health disorders, level of functioning (however defined), language spoken, race and ethnicity, gender, age, education, income, medical conditions, and health insurance status. The agency would like to be able to produce national estimates based on the data. The periodicity of the data collection has not been determined yet, and SAMHSA would like input on the ideal frequency for this subject matter.

SAMHSA has considered several possible data collections approaches, Russell said. One option would be to add questions on recovery to SAMHSA's existing National Survey on Drug Use and Health (NSDUH) survey. However, he noted, that survey is already very long, and adding a substantial number of new questions would require dropping something else. Another option would be to reinstate the Mental Health Surveillance Study (MHSS), which was a small study conducted as a follow-on to the NSDUH between 2008-2012. The MHSS involved asking in-depth questions of a subset of the NSDUH respondents as part of an additional interview, and a similar mechanism could work for questions about recovery. The third option described by Russell was to develop a new data collection program. This may be necessary, for example, if the expert view is that a longitudinal design is needed to properly measure recovery. Finally, SAMHSA could potentially rely on secondary data sources to produce estimates, if data that meet SAMHSA's goals already exist. Russell mentioned that the MHSS data were used to develop model-based estimation procedures that were then applied to the NSDUH data. A similar strategy could work for producing estimates of recovery. Model-based estimation procedures could also be applied to other potential data sources.

D.E.B. Potter (Office of The Assistant Secretary for Planning and Evaluation) added that across the U.S. Department of Health and Human Services (DHHS) there is a desire to measure the quality of health care that is delivered to populations with behavioral health needs, and measuring outcomes is a priority. In the area of quality measurement, person-reported outcomes are important, and the discussions at the workshop will likely also inform a variety of efforts across DHHS.

Kim Mueser (Boston University) asked Russell to clarify whether SAMHSA's interest is in recovery from any diagnosable mental illness or in severe mental illness? Russell said that SAMHSA is interested in both, as well as recovery from substance use disorders. However, he acknowledged that it may be very difficult to ascertain severe mental illness within the framework of some of the potential approaches he discussed, such as the current NSDUH. Mueser noted that limiting the data collection to people who receive some type of disability benefits, such as Social Security Disability or Supplemental Security Income, due to a mental disorder may be more feasible then including everyone who has had a diagnosable mental illness. The population receiving disability benefits due to a mental disorder is more likely to include individuals with schizophrenia or a major persistent mood disorder

WORKSHOP CHARGE

The specific statement of task for the workshop, shown in Box 1-2, was developed on the basis of the charge for the overall project, which was to expand data collections on several behavioral health topics. The main goals of the workshop were to discuss options for collecting data and producing estimates of recovery from substance use and mental disorder, including available measures and associated possible data collection mechanisms.

BOX 1-2

STATEMENT OF TASK

A steering committee will organize a public workshop that will feature invited presentations and discussions on options for expanding SAMHSA's behavioral health data collections to include measures of recovery from substance use and mental disorder. The discussion will explore new measures and efficient mechanisms for collecting the data. Possibilities include adding new measures to existing surveys, initiating new data collections, or implementing model-based estimation procedures that take advantage of existing data sources, in the event that primary data collection methods are cost-prohibitive or not necessary. Survey and questionnaire design tradeoffs, as well as the potential impact of any changes to existing surveys, will also be discussed. An individually authored summary of the presentations and discussions at the workshop will be prepared by a designated rapporteur in accordance with institutional guidelines.

ORGANIZATION OF THE REPORT

This summary describes the workshop presentations and the discussions that followed each topic. The workshop agenda in Appendix A, and biographical sketches of the presenters and of the steering committee members are in Appendix B.

Chapter 2 discusses the policy context and key concepts associated with measuring recovery. A discussion of the policy context of measuring recovery from substance use is followed by a similar discussion for measuring recovery from mental disorders. Chapters 3-5 focus on definitions of recovery and possible ways of operationalizing the concept. Chapter 3 describes SAMHSA's working definition of recovery. Chapter 4 discussed definitions, operationalization challenges and implications for measurement specific to measuring recovery from substance. Chapter 5 discusses similar issues in the context of recovery from mental disorders. The concept of positive mental health is also introduced in Chapter 5.

Chapter 6 covers existing measures of recovery, with separate sections dedicated to measures of recovery from substance use and from mental disorders. Chapter 7 discusses data collection designs, including a brief overview of SAMHSA's recovery measurement pilot study, and an overview of different data collection strategies suitable for measuring recovery from both substance use and mental disorders. Tradeoffs associated with different data collection strategies are also described. Chapter 8 summarizes the key themes that emerged from the discussions and highlights possible next steps.

This summary has been prepared by the workshop rapporteur as a factual summary of what occurred at the workshop. The steering committee's role was limited to planning and convening the workshop. The views contained in the summary are those of individual workshop participants and do not necessarily represent the views of all workshop participants, the steering committee, or the National Academies of Sciences, Engineering, and Medicine.

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Policy Context and Key Concepts

Two presentations at the workshop focused on the policy context and key concepts associated with recovery. Keith Humphreys (Stanford University) discussed issues related to recovery from substance use and Kenneth Wells (University of California, Los Angeles) discussed issues related to recovery from mental disorders.

POLICY CONTEXT OF MEASURING RECOVERY FROM SUBSTANCE USE

Keith Humphreys began by noting that recovery is embraced as a policy goal in the United States. Similarly, Scotland, England and Wales consider recovery a guiding goal of drug policy, and other countries, such as Australia, have discussed incorporating this concept into their policies. He noted that in the U.S. health care system, due in part to the Affordable Care Act and some recent changes in Medicaid, there is a desire to fund recovery support services even if these have not yet been fully defined. He added that the Surgeon General's report on substance use disorders, currently under development, also includes a chapter on recovery. From a grassroots perspective, there has been an increase in people identifying with being part of a recovery movement.

Humphreys said that the need to measure recovery is partly scientific, but it is also related to the desire of a group of people to be counted. The grassroots-based political push for measuring recovery raises the question of how to design studies that are credible, valid, and use measures that are meaningful to those who have gone through the experience. In his summary of the basic dilemma, he described recovery as a concept that comes from outside of medicine. Medicine has expertise in measuring disease, the absence of disease symptoms, and impairments. Medicine also has some expertise in measuring rehabilitation, generally defined as a person restored to a previous state of health. However, recovery is different from all of these concepts. Recovery is not just the absence of illness and it is not exactly rehabilitation (which means "to be made healthy again") because some people say that they were never healthy before recovery, and others say they consider themselves healthier afterwards. Humphreys said that coming up with a good definition of recovery is a scientific problem in some respects, but in other respects it is a credibility problem.

Humphreys argued that there are some previous studies that scientists can rely on to inform the validity of the data collection approaches they are considering. High-quality ethnographic and qualitative studies have been conducted by Alain Cerclé, Norman Denzin, David Rudy, Ramona Asher, and Carole Cain, and these contain rich information on lived experiences of recovery. A small number of quantitative surveys have asked recovering people how they define recovery, and these are discussed in detail by Christine Grella and Alexandre Laudet (see Chapter 4). In addition, expert groups of researchers, clinicians and recovering people have written consensus guidelines defining recovery.

Humphreys said that the concept of recovery is used in at least three different ways:

- a process that individuals with an addiction experience,
- a desirable outcome for addicted individuals, and
- a cultural and political movement or set of values.

For the purposes of the current SAMHSA initiative to measure recovery, Humphreys argued that the second interpretation is most relevant. In other words, the interest is in a desired outcome and recovery rates in the population.

Humphreys next discussed several definitions of recovery. The Betty Ford Institute Consensus Conference, which included the often overlapping groups of people in recovery, advocates, clinicians, and academics, developed this definition: "Recovery from substance dependence is a voluntarily maintained lifestyle characterized by sobriety, personal health and citizenship."[2] Humphreys pointed out that "voluntarily maintained" means that the definition does not include people who were incarcerated and could not use substances. Sobriety means that the definition assumes no substance use at all. Finally, personal health and citizenship imply that recovery is viewed as not just the absence of symptoms, but also as some kind of broad well-being and engagement with community roles and responsibilities.

Another definition comes from the U.K. Drug Policy Commission, which described recovery as: a process, characterized by voluntarily maintained control over substance use, leading towards health and well-being.[3] This definition was in a sense a response to the Betty Ford definition, and it is very similar. However, the "voluntarily maintained control over substance use" in the U.K. definition allows for the possibility of moderate drinking while in recovery. The U.K. definition also emphasizes that individuals who are participating in methadone treatment can be considered in recovery, which Humphreys noted is a subject of debates in both the United States and in the United Kingdom.

The final definition noted by Humphreys was the Connecticut Community for Addiction Recovery definition: "You are in recovery if you say you are."[4] Humphreys said that this definition can be interpreted in two ways. One interpretation is that it reflects a grassroots political movement that aims to be inclusive, and from this perspective efforts to narrow the definition may not be well received by those who perceive it to be exclusionary. Another interpretation of the definition is that it reflects the view that recovery is subjective and self-determined.

Humphreys said that there are three challenges associated with the definitions. One of them is that there is some disagreement about whether individuals who are moderate substance users can be in recovery. The second is that there is disagreement about whether people who abstain from substances with the aid of medication can be considered to be in recovery. And third, not everyone agrees that definitions of recovery can be standardized at all.

Humphreys pointed out that on these questions there is sometimes a departure in views between those with a lived experience and those without a lived experience. Government and academic researchers tend to want to be inclusive, and while this is a noble goal, it overstates the

[2]The Betty Ford Institute Consensus Panel (2007). What is recovery? A working definition from the Betty Ford Institute. *Journal of Substance Abuse Treatment.* 33: 221–228.

[3]The UK Drug Policy Commission Recovery Consensus Group (2008). *A Vision of Recovery Policy Report*. http://www.ukdpc.org.uk/wp-content/uploads/Policy%20report%20-%20A%20vision%20of%20recovery_%20UKDPC%20recovery%20consensus%20group.pdf [July 2016]

[4]See: http://ccar.us/#about [July 2016].

differences among those with lived experience in how they think about recovery. Humphreys argued that SAMHSA's definition of recovery is an example of a definition that is broad to an extent that it loses its meaning for those who are in recovery because it includes a wide range of people and experiences that they do not associate with recovery.

Humphreys said that the widespread availability of the internet has provided researchers with opportunities to collect data from large numbers of people in recovery and better understand their perspectives. One of these studies described by Humphreys is the What is Recovery? Study.[5] He argued that the study's findings illustrate substantial agreement among people who consider themselves in recovery in how they define recovery. Several elements of recovery were endorsed by 90 percent or more of the respondents in this study as elements that belong in the definition of recovery. The elements included: no use of alcohol; no abuse of prescription medications; a realistic appraisal of one's own abilities and limitations; being honest with oneself; living a life that contributes to society, to one's family, or to one's betterment; and being grateful. There was less agreement on some items, for example on whether abstaining from tobacco belongs in the definition of recovery, with 64 percent of the respondents endorsing this item. Humphreys urged caution to not lose track of the relative agreement among those with lived experience and to avoid definitions that are so broad that are meaningless or divorced from lived experience.

As Humphreys indicated, one of the challenges associated with measuring recovery is that there is no agreement about whether the recovery experience can be standardized or whether it is entirely subjective. He argued that the solution to this problem is to embrace it, in other words, to always include a simple question that asks whether the person considers themselves to be in recovery from addiction. He added that some of the surveys that measure recovery with questions such as "have you ever had a problem with drugs or alcohol and now no longer think that you do?" are criticized because many people who would be counted as in recovery on the basis of that question, do not think of themselves as in recovery, and conversely, many people who would not be counted as in recovery, consider themselves to be in recovery by their own definition. Consequently, it is important to assure that people who are classified as in recovery in a study would recognize themselves as such: if they do not, the study will have both a validity problem and a credibility problem.

Christine Grella (University of California, Los Angeles) commented that recovery has a very politicized, subjective meaning, which can be seen when subgroup responses to the questions in the What Is Recovery? Study are analyzed. For example, some people consider themselves as having had a problem and no longer do, but they do not like the term recovery because of the association with traditional 12-step programs. She argued that because of issues of this type, more inclusiveness may be necessary. (See Chapter 4 for further details about the results from the What Is Recovery? Study.)

Humphreys noted that in some cases comparisons across groups are difficult because the size of some of the groups is fairly small. He agreed with Grella that it is important to develop an approach that captures everyone who is in recovery, but he argued that there is a the risk associated with a definition that becomes so broad that people with lived experience are no longer able to discern what it is that is being talked about and do not recognize themselves in the experience.

[5]Kaskutas, L.A., Borkman, T.J., Laudet, A., Ritter, L.A., Witbrodt, J., Subbaraman, M.S., Stunz, A., Bond, J. (2014). Elements that define recovery: the experiential perspective. *Journal of Studies on Alcohol and Drugs*, 75, 999–1010.

Alexandre Laudet (Center for the Study of Addictions and Recovery, National Development and Research Institutes, director emeritus) said that in one of the studies that she was involved in they did hair sample analysis to ascertain abstinence from both drugs and alcohol and found that people who have not used any substances in a while would say that they are not in recovery. When asked about this, they said that they did not consider themselves in recovery because they did not "go to meetings," which underscored Grella's point about the strong perception of recovery as participation in a 12-step program. Laudet added that it is generally very difficult to recruit participants for research on recovery who are not in a 12-step program, even when terms other than recovery are used. She said that this was the case even in the What Is Recovery? Study, which was conducted over the Internet and aimed to include a broad range of respondents. Humphreys agreed that there is a strong association between the word recovery and 12-step programs, but he argued that it is still important to ask questions that allow one to measure recovery in a particular study.

Wilson Compton (National Institutes of Health) noted that this discussion seems to suggest that a study to measure recovery should include multiple approaches to asking the questions, one of which would be to simply ask about whether the person identifies herself or himself as being in recovery. The challenge for SAMHSA will be to decide how much time can be allocated to measuring recovery as part of any overall questionnaire. He added that the problem is similar to that associated with measuring sexual behavior and the distinction between the behavior and identity of being gay, lesbian, or bisexual. Given that there might be meaningful differences between groups of people who respond differently, the ability to distinguish between behavior and identity may be an important minimum requirement for a study.

Kim Mueser (Boston University) agreed with Humphrey's point that there is a fair amount of agreement about how recovery from substance use is defined. It seems that there is agreement that not using substances is at the center of the definition, even if some people may be using a small amount of one substance or another. There is also agreement that the lack of use is associated with improvement in functioning. Mueser noted that this definition appears to be in line with the traditional medical definition of recovery, that is, the determination that a person does not have a substance use disorder. He argued that if it is clear what is meant by recovery from a substance use disorder, it is not obvious that measuring a subjective identity is necessary.

Humphreys replied that there are political reasons behind this that are important. People want to be counted and acknowledged, and they do not necessarily recognize themselves in studies that omit the subjective identity question. He agreed with Compton that this issue is similar to wanting to count how many people have sexual partners of different types, but also needing to measure how many people describe themselves as gay or lesbian. He further argued that this consideration is particularly important for a taxpayer-funded initiative, because people often feel disregarded by the government, disregarded in the accounts of addiction, and disregarded in official statistics. They often argue that there is a need to understand addiction and recovery in a way that goes beyond the medical view and the symptoms, that also factors in other aspects of the process that are important to them, such as repairing families, making amends, becoming an active member of their communities, and volunteering.

Benjamin Druss (Emory University) noted that some of the specific aspects of the definitions described are specific to recovery from substance use disorders, and he wondered whether enough commonalities exist with recovery from mental health disorders to allow for a streamlining of the data collection design. Humphreys said that the spirit of recovery is similar for substance use and mental health, because both comprise a sense of optimism, a desire for

health, and a strength-based perspective. However, the specifics are not the same and that represents a measurement challenge.

POLICY CONTEXT OF MEASURING RECOVERY FROM MENTAL DISORDER

Kenneth Wells (University of California, Los Angeles) discussed the policy issues surrounding recovery from mental disorders, which he argued is important, because it may ultimately determine what needs to be measured and how measured outcomes are used. He pointed out that his presentation was based on input from a large number of research collaborators and community partners.

Wells reminded workshop participants of the World Health Organization definition of mental health: "a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community."[6] He argued that this broad definition is similar to the idea of recovery, and, in particular, the New Freedom Commission on Mental Health vision of recovery as a process in which people (with mental illness) are able to live, work, learn, and participate fully in their communities.[7]

Wells described three broad categories of definitions for recovery from mental disorders: clinical, research, and consumer or survivor. The clinical definition of recovery emphasizes symptom remission, return to functioning, and not using maintenance medication.[8] An example of a definition from a research context focuses on sustained symptom remission that lasts more than 2 years, engagement in role activities, such as work and school, living independently, and age-appropriate relations.[9] The consumer or survivor definitions focus on the process (rather than the outcome) and on a model of patient-centered approach to treatment.[10] Consumer definitions also tend to emphasize strength-based qualities: hope, respect, and empowerment. Wells underscored that SAMHSA will have to be intentional about which type of definition, or mix of definitions, to use.

Wells also noted several life-stage and cultural issues that should be considered in the context of defining recovery. First, as an earlier workshop highlighted,[11] the definition of disability for children is not well established, and that makes it more important to understand the context, the social risk factors, and the social determinants for younger age groups. Second, research has documented racial and ethnic biases in the determination of diagnosis and impairment across age groups, which has implications for recovery. Finally, there are disparities

[6]See: http://www.who.int/features/factfiles/mental_health/en/ [May 2016].

[7]See: https://store.samhsa.gov/shin/content/SMA03-3831/SMA03-3831.pdf [May 2016].

[8]Torgalsbøen A. (2005) What is recovery in schizophrenia? In: Davidson L, Harding C, Spaniol L, editors. *Recovery From Severe Mental Illnesses: Research Evidence and Implications for Practice. Vol 1.* Boston, Mass: Center for Psychiatric Rehabilitation, Sargent College of Health and Rehabilitation Sciences, Boston University. p. 302-315.

[9]Liberman, R.P. and Kopelowicz, A. (2002). Recovery from schizophrenia: A challenge for the 21st century. *International Review of Psychiatry*, 14: 245-255.

[10]Bellack, A.S. (2006). Scientific and consumer models of recovery in schizophrenia: Concordance, contrasts, and implications. *Schizophrenia Bulletin*, 32(3): 432-42.

[11]National Academies of Sciences, Engineering, and Medicine. (2016). *Measuring Serious Emotional Disturbance in Children: Workshop Summary.* K. Marton, Rapporteur. Committee on National Statistics and Board on Behavioral, Cognitive, and Sensory Sciences, Division of Behavioral and Social Sciences and Education. Board on Health Sciences Policy, Institute of Medicine. Washington, DC: The National Academies Press.

in the community and social contexts in which people live, and those characteristics also influence recovery.

Wells cited several papers and books that discuss the history of policies related to recovery from mental disorders.[12] Most relevant to the current policy context is the Mental Health Parity and Addiction Equity Act of 2008 and its interface with the Affordable Care Act, which highlights the dynamic policy context for the current measurement goals.[13] Wells noted that there is limited early evidence of improved access to mental health and addiction care in recent years, but there is evidence of some financial relief. Gaps have been noted in terms of specialty providers in networks, and there is an apparent lack of parity in some plan descriptions. In addition, concern about stigma remains an issue. Another issue noted by Wells is related to gaps in reinstituting Medicaid coverage after reentry for people who have been involved with the criminal justice system, who tend to have high rates of substance use disorders and serious mental illness.

Wells highlighted a number of additional developments and issues relevant to the health and social policy contexts and the interface of the two, some of which may promote recovery or potentially have an adverse effect, if they direct attention elsewhere:

- Medicare Accountable Care Organizations demonstration programs
- Medicaid health homes
- "co-location" grants
- funds to improve the mental health and substance use capacity of federally qualified healthcare centers
- dual eligible financial integration demonstration
- Medicaid expansion and waivers (including, integrated care, "whole person")
- U.S. Department of Veterans Affairs' integrated care and homelessness initiatives
- social and behavioral risk factors in electronic health records for meaningful use
- Centers for Medicare and Medicaid Services performance-based financing
- community behavioral health centers and regulations
- Centers for Medicare and Medicaid Services Medicaid funding for housing
- Accountable Health Communities demonstration programs
- Robert Wood Johnson Foundation Culture of Health Initiative, a civic action focus for equity
- Patient-Centered Outcomes Research Institute patient-centered focus

In addition to national initiatives, Wells noted that state efforts can also have implications for recovery. For example, the Oregon Medicaid experiment was found to decrease depressive symptoms, but it also increased emergency room use.[14] The expanded universal coverage in Massachusetts was also found to have a positive effect on mental health outcomes.[15]

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[12]See Braslow, J.T. (2013). The manufacture of recovery. *Annual Review of Clinical Psychology*. 9:781–809; Frank, R.G. and Glied, S.A. (2006). *Better But Not Well.* Baltimore, MD: John Hopkins University Press; Grob, G.N. (1994). *The Mad Among Us: A History of the Care of America's Mentally Ill*. New York: Free Press.

[13]Barry, C.L. and Huskamp, H.A. (2011). Moving beyond parity — Mental health and addiction care under the ACA. *New England Journal of Medecine*, 365, 973-975.

[14]See Baicker, K., Taubman, S.L., Allen, H.L., Bernstein, M., Gruber, J.H., Newhouse, J.P., Schneider, E.C., Wright, B.J., Zaslavsky, A.M., and Finkelstein, A.N. (2013). The Oregon experiment—Effects of Medicaid on clinical outcomes. *New England Journal of Medicine*, 368, 1713-1722; Taubman S.L., Allen, H.L., Wright, B.J.,

Wells highlighted the California Mental Health Services Act as possibly the most prominently recovery-oriented state initiative. The initiative consists of a 1 percent tax on personal incomes over $1 million, which is used for recovery-focused programs. These programs range from full-service partnerships to lower levels of care, with a focus on recovery. Wells noted that there are difficulties with moving clients forward to lower levels of care because many of them are very ill. However, there is some evidence that full-service partnerships decrease homelessness, the number of days spent in jail days, and the number of hospital inpatient days.

In addition to national and state initiatives, Wells also discussed several local programs with implications for recovery. The Los Angeles County Health Neighborhood Initiative reflects the understanding that if improved functioning is the goal, then sometimes social policy changes are needed in addition to health policy changes. The initiative involves integrating services across county agencies for behavioral health clients and supporting communities in addressing social determinants of behavioral health. For example, one program that is part of this effort focuses on secondary trauma prevention.

Another local initiative is the ThriveNYC initiative in New York City, which is based on identifying key new strategic directions that align multiple stakeholders to advance a public health approach to mental health. Wells said that there are more than 50 programs to exemplify and advance these new directions in New York City.

Wells noted that both the Los Angeles and New York City initiatives were to some extent based on the Community Partners in Care community-based demonstration in Los Angeles, for which he was the principal investigator.[16] That project focused on quality-improvement programs for depression and involved a randomized demonstration of multisector coalitions for community engagement and planning in comparison with expert assistance. The study found that the community coalition model resulted in improved 6-month mental health quality of life, physical health, and mental wellness. It also reduced behavioral health hospitalizations and the risk of homelessness. Wells commented that these are all aspects of recovery under a broad definition, assessed in this study at the individual level.

Wells concluded by saying that recovery is a broad concept, and it is affected by the perspective of stakeholders. Changes in health insurance policy, services delivery policy, social policy, community culture, a variety of programs, and their integration across federal, state, and local levels are all relevant in the context of recovery.

Hortensia Amaro (University of Southern California) commented that it is useful to acknowledge that recovery is dependent on context, which includes the service delivery system

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Baicker, K., and Finkelstein, A.N. (2014). Medicaid increases emergency-department use: Evidence from Oregon's Health Insurance Experiment. *Science*, 343(6168), 263-268.

[15]Courtenmanche C.J. and Zapata, D. (2013) Does universal coverage improve health? The Massachusetts Experience. *Journal of Public Analysis and Management*, 33(1), 36-69.

[16]See Wells K.B., Jones, J., Chung, J.B., Dixon, E.L., Tang, L., Gilmore, J., Sherbourne, C., Ngo, V.K., Ong, M.K., Stockdale, S., Ramos, E., Belin, T.R., Miranda, J. (2013). Community-partnered cluster-randomized comparative effectiveness trial of community engagement and planning or resources for services to address depression disparities. *Journal of Geneneral Internal Medicine*, 28(10), 1268-1278; Miranda, J., Ong M.D., Jones, L., Chung, B., Dixon, E.L., Tang, L., Gilmore, J., Sherbourne, C., Ngo, V.K., Stockdale, S., Ramos, E., Belin, T.R., Wells, K.B. (2013). Community-partnered evaluation of depression services for clients of community-based agencies in under-resourced communities in Los Angeles. *Journal of General Internal Medicine*, 28(10), 1279-1287; Chung B., Ong, M., Ettner, S.L., Jones, F., Gilmore, J., McCreary, M., Sherbourne, C., Ngo, V., Koegel, P., Tang, L., Dixon, E., Miranda, J., Belin, T.R., Wells, K.B. (2014). 12-Month outcomes of community engagement versus technical assistance to implement depression collaborative care: A partnered, cluster, randomized, comparative-effectiveness trial. *Annals of Internal Medicine*, 161(10 Suppl), S23-34.

and resources in the community. She underscored that the social determinants of health often differ across populations. Wells replied that in work he conducted in post-Katrina New Orleans, the disaster meant an immediate change in community context for people with severe mental illness. Had there been recovery measures that were sensitive to both the individual and the community, it would have been very useful at that time.

Dean Kilpatrick (Medical University of South Carolina) noted that there are several relevant concepts in this discussion. One is the subjective self-labeling of being in recovery or having recovered. The other is the objective question of how well the person is doing. However, there needs to be a comparative measure that factors in how the person was doing before recovery. An interesting methodological question is whether it is possible to measure how a person is doing now and how they were doing before, without having to do a longitudinal study. He also argued that the methodological implications of differences between people who label themselves as in recovery and those who do not are important to examine.

Wells said that an additional complicating factor in mental health recovery, and to some extent in addiction recovery, is the issue of stigma. Some people may not want to describe themselves as in recovery because that also discloses their diagnosis, and in the case of certain mental illnesses, such as schizophrenia, it is possible that they will never be completely free of symptoms. Thus, in that context the emphasis is on whether the person can function and enjoy life, and it is important not to focus the definition simply on symptom relief.

3

SAMHSA's Definition of Recovery

After the initial introduction (Chapter 1) of SAMHSA's working definition of recovery provided by Neil Russell (SAMHSA), Steven Fry (SAMHSA) and Donna Hillman (SAMHSA) discussed the agency's definition in more detail. Fry began by noting that SAMHSA's Center for Mental Health Services began working on a definition of recovery in 2004, focusing at that time on mental health. In 2009 the agency commissioned an environmental scan of measures and instruments to gain an understanding of what the scientific community was using as definitions of recovery. SAMHSA's definition was developed in collaboration with a large group of stakeholders who were brought together in 2010. After a working definition was developed, the agency solicited public feedback.

Fry said that the current working definition (see Box 1-1 in Chapter 1) reflects that recovery is a process of change, not a static event. An individual's work to improve health and well-being, live a self-directed life, and strive to achieve full potential are all important aspects of recovery. He pointed out that living a self-directed life is particularly important for the mental health recovery community because opportunities for these individuals have often been limited. Fry recalled that when he was hospitalized as an adolescent with schizophrenia, he was told that he would never be able to work or have a family. To him, that was astonishing and lacking in hope. However, he went on to have a 30-year career in the mental health system, become a homeowner, and become a father.

Fry described the four dimensions that SAMHSA delineated as supporting life in recovery, shown in Figure 3-1. Home is a stable and safe place to live. Community is relationships and social networks that provide support, friendship, love, and hope. Purpose is meaningful daily activities, such as a job, school, volunteerism, family caretaking, or creative endeavors, and the independence, income, and resources to participate in society. Finally, health is overcoming or managing one's condition and symptoms.

Fry said that the four dimensions he described, along with a set of principles that will be described by Hillman (see below) are what guide decisions at SAMHSA about the design of programs and about how resources should be considered in their implementation. He argued that when these guidelines are applied to how resources are used, there are reductions in emergency room visits, reductions in incarceration or contacts with the correctional system, and increases in employment and in the rates of returning to school. He added that the people affected by these resource decisions are also found to enjoy life to a much greater degree.

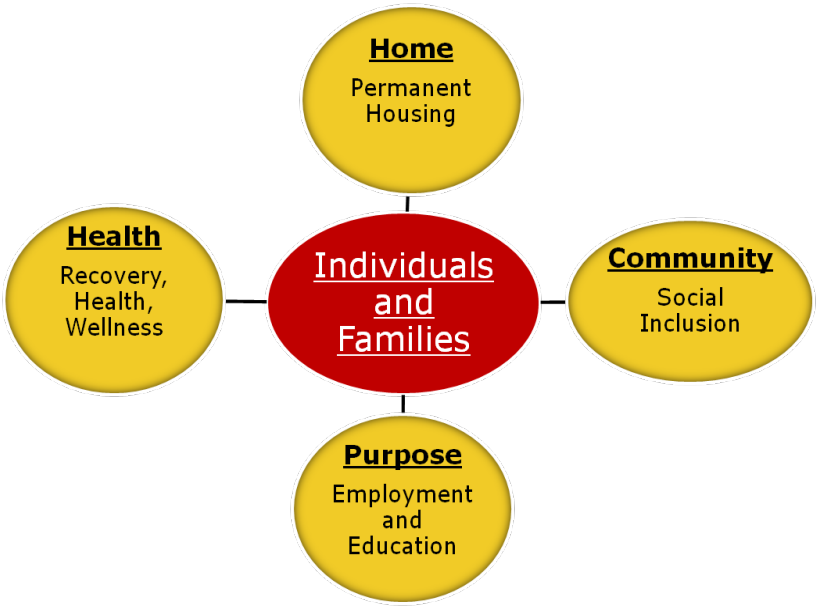

FIGURE 3-1 SAMHSA's four dimensions of recovery.
SOURCE: Workshop presentation by Steven Fry, February 2016.

Hillman began by saying that she is a person in long-term recovery and for her that means that for almost half of her life she has been free of alcohol and substance use. She agreed with previous speakers about the role of behavior in addiction and recovery. In her case, she said that there were specific linked behaviors that kept her in her addiction, and throughout her recovery there are behaviors that support that recovery. She also added that she does not associate recovery only with 12-step programs. She has not participated in a 12-step program; rather, there have been multiple pathways and multiple interventions that have assisted with her recovery. There have also been many markers in her life of being successful and moving forward.

Hillman pointed out that the four dimensions of recovery discussed by Fry are not only dimensions of recovery, but also of universal desires. People in recovery aspire to the same goals as everyone else, but they may have had a harder time achieving them. She noted that there is a general expectation across society that anyone can recover, although there are risks associated with the exacerbation of symptoms and there is the risk of relapse.

Box 3-1 summarizes the guiding principles of recovery developed by SAMHSA. Hillman said that the most important principle is hope, because without hope there is no recovery. Self-determination and self-direction are also important foundations for recovery, as individuals define their own life goals. As Hillman's own experience illustrates, there are many pathways to recovery, and everyone's experience is different.

BOX 3-1

SAMHSA'S GUIDING PRINCIPLES OF RECOVERY

Recovery:

- emerges from hope
- is person-driven
- occurs via many pathways
- is holistic
- is supported by peers and allies
- is supported through relationship and social networks
- is culturally-based and influenced
- is supported by addressing trauma
- involves individual, family, and community strengths and responsibility
- is based on respect

SOURCE: SAMHSA's Working Definition of Recovery Updated http://blog.samhsa.gov/2012/03/23/defintion-of-recovery-updated [May 2016].

Many of the principles reflect characteristics and systems that need to be in place to support recovery. Recovery is holistic, and Hillman stressed a great need for integration between primary health care and behavioral health care. Peer support and the support of other allies are also important, as are relationships and social networks. From a measurement perspective, Hillman highlighted the fact that there are strong recovery community organizations that can be a great resource to researchers who are developing survey questions and want to reach out to potential study participants who are in recovery to test the questions.

Another guiding principle discussed by Hillman is that recovery is culturally based and influenced. Cultural background shapes a person's unique pathway to recovery, and services and programs need to be culturally grounded and adapted to the given context.

A less frequently discussed aspect of recovery on the list of SAMHSA's guiding principles is the need to address trauma. Hillman pointed out that in addition to considering exposure to traumatic events, such as sexual abuse or child abuse, it is important to also consider historical trauma that may affect particular racial or cultural groups. Fry's example of being told as a child that he will never be able to have a job or a family is also a type of trauma from which one needs to recover.

A final guiding principle on SAMHSA's list is that recovery involves individual, family, and community strengths and responsibility. These resources and social determinants serve as foundations of recovery. Hillman noted that being treated with respect is also essential for people to begin the process of recovery and stay in recovery.

In conclusion, Hillman said that she does not think that recovery can be measured as one point in time. In treatment programs, recovery is often measured as people's improvement from admission to discharge, and it is expected that there will have been some progress towards improvement in that context. However, she argued that the focus of measuring recovery should be on impact. In other words, what is important is the impact of recovery on the person's life. Input from people in recovery can shed light on what factors contributed most to that impact and what were the markers of improvement. Hillman argued that a longitudinal perspective seems to be essential because even those who have been in recovery for many years continue to improve over time. She said that she describes herself as a person in long-term recovery because recovery is a process.

In terms of the population of interest for measuring recovery, Hillman said that SAMHSA has a good grasp on how many people are in treatment, but there is a large number of people in recovery who have not been counted. Reaching out to peer support recovery communities would be one avenue for reaching out to a broader population, beyond those individuals who are in treatment.

4

Defining and Operationalizing Recovery from Substance Use

This chapter summarizes a presentation by Christine Grella (University of California, Los Angeles) on definitions of recovery from substance use and their implications for measurement and a presentation by Alexandre Laudet (Center for the Study of Addictions and Recovery, National Development and Research Institutes, director emeritus) on what is known from research studies about how recovery is viewed by those who are in recovery from substance use.

DEFININITIONS OF RECOVERY FROM SUBSTANCE USE AND IMPLICATIONS FOR MEASUREMENT

Grella said that although in the 19th century people with alcohol use problems were often "locked away" in institutions, that was also a time of growing awareness of the social problems that stem from alcohol misuse and of the subsequent rise of temperance movements. The concept of recovery from alcohol problems dates to the emergence of mutual self-help organizations within the context of these temperance movements.

Grella said that there were two wings of temperance movements, and these are echoed in the recovery movements that followed. The Washingtonian Temperance Society was a nonsectarian group with methods centered around public testimonials and a public temperance pledge. The idea was that recounting one's past and affirming the present changed people's identity, and this is echoed in later views of the role of self-definition and a public proclamation of being recovered. By contrast, the evangelical temperance movement focused on gospel rescue missions, prayer meetings, and public proclamation of one's sinful nature and transformation. The influence of this movement is also evident in some of the modern-day conceptualizations of recovery.

Alcohol Anonymous was founded in 1935 and marked the beginning of a mass movement of mutual support groups for recovery. This movement also embodied the ritual of publicly proclaiming one's identity as an addict or an alcoholic and the sharing of one's stories from the past to illustrate the changes that have occurred in one's life.

Grella discussed the Jellinek curve, which originated based on interviews conducted with members of Alcoholics Anonymous in the 1940s. The curve illustrates a process of moving into addiction that involves increasingly problematic behavior, "bottoming out," and then a gradual recovery, with increasingly prosocial behaviors and engagement in recovery activities. Grella said that this model differs from contemporary views of recovery in a number of ways. For example, today there is more emphasis on intervening and averting a possible bottoming out. However, Grella noted that the model put forth the key concepts of trajectory, change, and stages.

Grella noted that telling one's story continues to play an important role in the context of recovery. She used the example of the Faces and Voices of Recovery advocacy organization,

which has a website where people can post their recovery stories. The International Quit & Recovery Registry is another website where recovery stories are posted. This latter website also serves as a platform for crowd-sourcing research on substance use recovery and a mechanism that provides an alternative to the clinical context for recruiting study participants. Grella said that studies on recovery tend to rely on clinical treatment samples, which means that they tend to have a higher representation of the relatively more severe cases. Alternative approaches that reach a wider group of people in recovery in the general population can help address this imbalance.

Grella said that there was an exponential increase over the past decade in the number of published scientific articles that have "recovery" or "recovered" in the title. The studies have used a variety of approaches to study recovery, including: developmental or life-course approaches, clinical indicators, and behavioral indicators in clinical and cohort studies. Grella discussed these approaches in detail, along with two longitudinal studies that she worked on, along with the What Is Recovery? Study.

Developmental or Life-Course Approaches

The first approach discussed by Grella was the developmental or life-course approach to studying recovery from substance use. Studies of this type often use cross-sectional survey data to look at the percentage of the population across age groups that falls into different categories of severity in terms of substance use. The findings tend to show that the onset of substance use disorders increases over time through the adolescent period, reaches its peak in early adulthood around the ages of 18 to 20, and then gradually declines over time. Figure 4-1 illustrates this trend.

The questions of interest to researchers include: What accounts for this movement into remission over time? What are the drivers of change? What is the role of the maturation process? What is the role of life events that occur at different stages of the life cycle? Grella noted several constructs that are particularly relevant in this research: natural recovery, turning points, and recovery capital.[17] Natural recovery refers to the finding that the majority of individuals who at some point meet the criteria for substance use disorders go into remission without any intervention. Turning points are life events, experiences, or role transitions (such as marriage, childbirth, employment, incarceration, and illness) that result in changes in the direction of pathways or persistent trajectories over the long term. Recovery capital refers to resources that individuals with substance use problems can use to cope with stressors and sustain recovery. This could include access to treatment services, 12-step groups, a supportive family, friends, and social networks.

Grella discussed an early study by Winick[18] that was influential in framing how the field thinks about changes associated with the recovery process, and which coined the term "maturing out" of narcotic addiction. The research relied on Federal Bureau of Narcotics records of people addicted to narcotics, examining data for the period between 1955 and 1960 (N = 45,391), to

[17]See Granfield, R., and Cloud, W. (2001). Social context and "natural recovery": The role of social capital in the resolution of drug-associated problems. *Substance Use and Misuse, 36*, 1543-1570; Laudet, A., and White, W. (2008). Recovery capital as prospective predictor of sustained recovery, life satisfaction, and stress among former polysubstance users. *Substance Use & Misuse*, 43, 27−54; Teruya, C., and Hser, Y.I. (2010). Turning points in the life course: current findings and future directions in drug use research. *Current Drug Abuse Review*, 3(3), 189-195; Waldorf, D. (1983). Natural recovery from opiate addiction: Some social-psychological processes of untreated recovery. *Journal of Drug Issues*, 13, 237-280.

[18]Winick, C. (1962). Maturing out of narcotic addiction. *Bulletin on Narcotics*, 14(1), 1-7.

determine what proportion were "inactive" at the end of the 5-year period, in 1960. Grella noted that using a 5-year period was common in other fields of medicine, such as cancer research, but in the context of recovery, there is a debate about the time period needed to reach a point after which the risk of relapse becomes significantly less likely. The study also had additional limitations pointed out by Grella, including its reliance solely on administrative records and that its lack of control for mortality.

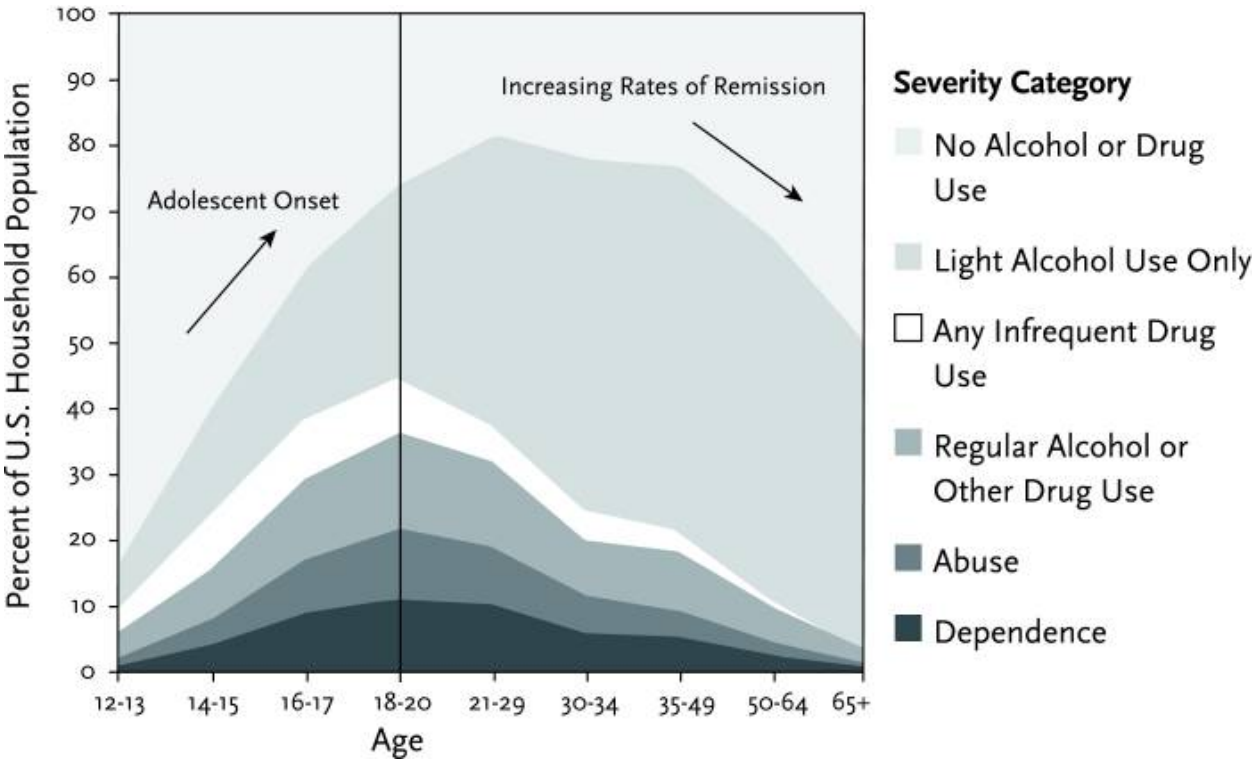

FIGURE 4-1 Substance use disorders over the life course.
SOURCE: Dennis, M., and Scott, C.K. (2007). Managing addiction as a chronic condition. *Addiction Science & Clinical Practice*, 4(1), 45–55. (Based on the 2001 National Survey of Drug Use and Health Data)

Winick found that at the end of the 5-year period, 16 percent of the cases were inactive. The inactive cases ranged in age from 18 to 76, and the average age at the point of inactivity was around 35. The duration of addiction ranged from 5 to 56 years, with an average duration of 8.6 years. The research pointed at developmental processes, and the author argued that people in young adulthood may be more vulnerable to substance use because of the pressures associated with the transition into adult roles and responsibilities. As people get older, these pressures diminish. He also identified several factors that influenced cessation: external circumstances; relationships jeopardized by drug use; weariness; personality and insight; and incapacitating physical problems. Winick hypothesized that maturation out of addiction occurs as a reflection of a person's life cycle and as a function of the length of the addiction.

Grella also described a study that reexamined the "maturing–out" hypothesis based on records and interviews with 248 opioid users who were treated at the Public Health Service Hospital in Fort Worth between 1964 and 1967 and followed up through 1975.[19] The study concluded that there was little evidence of maturational change in terms of a therapeutic process and that external circumstances that propel people into recovery are more important. The authors identified five conditions that likely facilitated recovery among the population they studied: relocation away from usual source of drugs; evangelical religious participation; employment with drug abuse treatment agency; probation or parole for 1 year or more; and alcohol substitution. Grella commented that polysubstance use complicates the conceptualization of recovery. Alcohol use in conjunction with other substance use is common among populations studied; in addition, Grella said, studies conducted today need to determine how to factor in marijuana use for medical reasons and whether such use violates "abstinence" among those in recovery from other substance use.

The study also looked at methadone maintenance, which, as Grella pointed out, raises the question of whether to integrate medication-assisted treatment in the definition of recovery. Traditionally, this factor was not included in the definition, but that approach is changing, and there is a need to better understand whether people who are in medication-assisted treatment think of themselves as being in recovery.

Another set of studies described by Grella was Vaillant's longitudinal studies of male heroin addicts and alcoholics.[20] His study samples included comparison groups and were followed over many decades. For example, the study of alcoholics included 268 Harvard undergraduates and 456 nondelinquent, socially disadvantaged Boston adolescents, and the participants were followed from age 20 to age 70–80. Vaillant also relied on records-based data and interviews with the participants. He found that at age 70, between 21-32 percent of surviving alcoholics were abstinent, and 11-12 percent were still abusing alcohol. Grella pointed out that findings of approximately one-third of the population in stable abstinence during follow-up appears to be common across studies. She noted that Vaillant's study of heroin users also pointed at 3-5 years as the threshold that seemed to indicate stability, which the author called "freedom from relapse." In the samples of both the alcoholics and heroin users, freedom from relapse was associated with community compulsory supervision; a substitute dependence; new relationships; and inspirational group membership, such as religion or Alcoholics Anonymous. Stable "pre-morbid" adjustment, especially employment, was the most predictive of the outcomes.

Clinical Indicators of Recovery

The second approach to studying recovery from substance use disorder discussed by Grella focused on clinical indicators of recovery, particularly use of the clinical criteria in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) to look at remission. Grella said that in the DSM-5 the criteria for remission from a substance use disorder are divided into two components: early remission and sustained remission. Among individuals with a lifetime

[19]Maddux, J.F., and Desmond, D.P. (1980). New light on the maturing out hypothesis in opioid dependence. *UNODC - Bulletin on Narcotics*, 1(002), 15-25.

[20]See Vaillant, G.E. (2003). A 60-year follow-up of alcoholic men. *Addiction*, 98(8), 1043–1051; Vaillant, G.E., and Milofsky, E.S. (1982). Natural history of male alcoholism IV. Paths to recovery. *Archives of General Psychiatry*, 39(2):127-133; Vaillant, G.E. (1988). What can long-term follow-up teach us about relapse and prevention of relapse in addiction? *British Journal of Addiction*, 83(10), 1147–1157; Vaillant, G.E. (1966). A 12-year follow-up of New York addicts: IV. Some determinants and characteristics of abstinence. *American Journal of Psychiatry*, 123, 573-584.

substance use disorder, early remission is at least 3 but less than 12 months with no symptoms, except craving, and sustained remission is at least 12 months with no symptoms, except craving.

Grella began by discussing several studies that focused on clinical indicators of recovery using data from the National Epidemiologic Survey on Alcohol and Related Conditions (NESARC). She noted that the NESARC has excellent diagnostic data, and it is frequently used to study remission or recovery based on DSM criteria. The NESARC includes a baseline interview that collects in-depth information on lifetime history, including lifetime substance use disorders, onset, remission, and associated information. The NESARC also includes a 3-year longitudinal component. Grella pointed out that some of the questions are asked both retrospectively and prospectively, and the responses tend to differ, which presents a challenge for researchers.

One study conducted by Quintero and colleagues used baseline NESARC data retrospectively looked at the probability of remission over the period of time anchored to the onset of dependence for four substances, nicotine, alcohol, cannabis and cocaine.[21] The study found that the probability of remission increases over time, most rapidly during the first 10 years following the onset of the dependence disorder. Grella noted that this finding is in line with the maturing out theory discussed earlier. Given that the onset of the disorders is often before a person's early 20s, remission tends to happen in people's mid-30s when adult roles and responsibilities come into play. Quintero and colleagues found more gradual slopes of remission for nicotine and alcohol than for cannabis and cocaine. Grella reminded workshop participants that many people who meet the criteria for a disorder go into remission without having sought treatment and without having interacted in a recovery context: thus, they may not identify as being in recovery, even though they might meet the criteria based on their reported symptoms. This phenomenon represents a measurement challenge.

As discussed earlier, she noted, one conceptual challenge is related to deciding whether recovery requires strict abstinence or whether partial, non-problematic substance use can be included. One study led by Dawson and her colleagues used NESARC data to look at this question by classifying respondents into categories of recovery based on the DSM criteria.[22] Among those with lifetime alcohol use disorder, Dawson and colleagues created the following categories, according to past-year status:

- *still dependent*: met three or more positive criteria for alcohol dependence
- *partial remission*: did not meet the criteria for alcohol dependence, but reported one or more symptoms of either alcohol abuse or dependence
- *asymptomatic risk drinker*: past-year risk drinker, but no symptoms of either abuse or dependence (for men this meant drinking on average more than 14 drinks a week or drinking 5 or more drinks in a single day one or more times in the past year; for women, this meant drinking on average more than 7 drinks a week or drinking 4 or more drinks in a single day one or more times in the past year)
- *low-risk drinker*: non-risk drinker with no symptoms of either abuse or dependence

[21]Quintero, C.L., Hasin, D.S., de Los Cobos, J.P., Pines, A., Wang, S., Grant, B.F., and Blanco, C. 2010). Probability and predictors of remission from life-time nicotine, alcohol, cannabis or cocaine dependence: Results from the National Epidemiologic Survey on Alcohol and Related Conditions. *Addiction*, 106, 657–669.

[22]Dawson, D.A., Stinson, F.S., Chou, P.S., Huang, B., and Ruan, W.J. (2005). Recovery from DSM-IV alcohol dependence – United States, 2001–2001. *Addiction*, 100, 281 -292.

- *abstainer*: did not consume any alcohol

Asymptomatic risk drinkers, low-risk drinkers, and abstainers were classified as being in full remission. Low-risk drinkers and abstainers were classified as being in full remission and in recovery. The researchers compared the characteristics of the individuals in the two recovery categories, abstinent recovery and non-abstinent recovery, and Grella described some of the findings. For example, the study found that having a child under age 1 in the household was positively associated with abstinent recovery, but only marginally associated with non-abstinent recovery. Attending religious services weekly was positively associated with both abstinent and non-abstinent recovery. Seeking help that included 12-step participation was predictive of abstinent recovery, but not of non-abstinent recovery.

In another study, Dawson and colleagues used NESARC prospective data to examine the age-related correlates of drinking cessation among regular drinkers.[23] Some of the findings highlighted by Grella were the positive association between drinking cessation and the onset of liver disease among drinkers between the ages of 18-54, and the negative association between drinking cessation and higher socioeconomic status among drinkers over age 55. A college education (in comparison with a high-school education) was negatively associated and smoking cessation was positively associated with drinking cessation among all age groups.

Another study described by Grella revisited the maturing out theory using longitudinal NESARC data.[24] Verges and his colleagues analyzed data for individuals who in the follow-up wave met criteria for a drug use disorder in order to examine whether rates of persistence changed with age. They found that persistence is relatively stable across age. However, they observed a strong negative correlation between age and recurrence and between age and onset of a new disorder.

Behavioral Indicators of Recovery in Clinical and Cohort Studies

A third category of studies described by Grella focused on behavioral indicators of recovery from substance use disorder in clinical and cohort studies; these studies tended to focus in particular on abstinence and psychosocial functioning. One study of this type used a sample of patients treated for substance use disorder in a managed care system.[25] Follow-up data were obtained from patients 1, 5, 7 and 9 years after intake. The study defined remission as abstinence in the past 30 days or nonproblematic substance use. Nonproblematic substance use was defined as: drinking four or fewer times in the previous month; not having five or more drinks on any given day; not using marijuana more than once; not using any drug other than alcohol or marijuana; and not having suicidal ideation, violent behavior, or serious conflict with friends, family, or colleagues. Grella noted that the multicomponent definition used in this study goes beyond clinical criteria and attempts to integrate other measures of functioning.

A similar multicomponent approach used a latent factor that combines several individual indicators with shared variance was done by Garner and colleagues, using data from the

[23]Dawson, D.A., Goldstein, R.B., and Grant, B.F. (2012). Prospective correlates of drinking cessation: Variation across the life-course. *Addiction, 108,* 712–722.

[24]Vergés, A., Jackson, K.M., Bucholz, K.K., Grant, J.D., Trull, T.J., Wood, P.K., and Sher, K.J. (2013). Refining the notion of maturing out: Results from the National Epidemiologic Survey on Alcohol and Related Conditions. *American Journal of Public Health*, 103(12), e67–e73.

[25]Chi, F.W., Parthasarathy, S., Mertens, J.R., and Weisner, C.M. (2011). Continuing care and long-term substance use outcomes in managed care: Early evidence for a primary care-based model. *Psychiatric Services*, 62:1194–2000.

Pathways Study.[26] Figure 4-2 shows the different individual factors that co-vary into a latent variable of recovery, their correlation coefficients, and the percentage of variance explained by each variable that is combined in the latent construct.

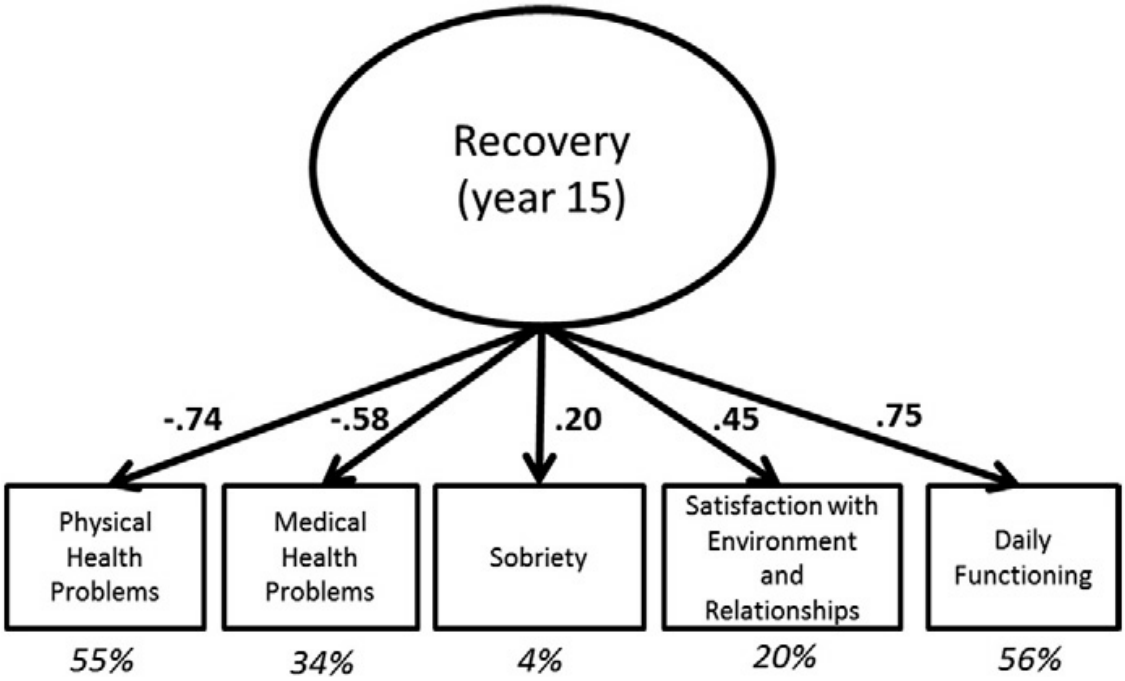

FIGURE 4-2 Latent measure of substance use recovery in Pathways Study.
SOURCE: Garner, B.R., Scott, C.K., Dennis, M.L., and Funk. R.R. (2014). The relationship between recovery and health-related quality of life. *Journal of Substance Abuse Treatment*, 47(4), 293-298.

Grella also discussed two longitudinal cohort studies that her group at the University of California at Los Angeles conducted. In one study, men with a history of heroin dependence who participated in the California Civil Addict Program between 1962 and 1964 were followed for over 30 years, in three waves of interviews.[27] The study defined stable recovery as 5 years of sustained abstinence from heroin. By the third follow-up wave (in 1996), approximately one-half of the sample members were deceased, and 22 percent could be described as in recovery.

Another study that Grella was involved in followed a cohort sample of individuals who participated in methadone maintenance treatment in California in the late 1970s.[28] This study was also longitudinal, and it used trajectory group analyses, which generated four clusters of

[26]Garner, B.R., Scott, C.K., Dennis, M.L., and Funk, R.R. (2014). The relationship between recovery and health-related quality of life. *Journal of Substance Abuse Treatment*, 47(4), 293-298.

[27]Hser, Y.-I., 2007. Predicting long-term stable recovery from heroin addiction: findings from a 33-year follow-up study. *Journal of Addictive Diseases*, 26, 51–60; Hser, Y.I., Hoffman, V., Grella, C.E., and Anglin, M.D. (2001). A 33-year follow-up of narcotics addicts. *Archives of General Psychiatry*, 58, 503-508; Hser, Y.I., Evans, L., Grella, C., Ling, W., and Anglin, M.D. (2015); Long-term course of opioid addiction. *Harvard Review of Psychiatry*, 23(2), 76-89.

[28]Grella, C.E., and Lovinger, K. (2011). 30-year trajectories of heroin and other drug use among men and women sampled from methadone treatment in California. Drug and Alcohol Dependence, 118, 251-258.

individuals with similar patterns of heroin use over time: rapid decrease in use (25 percent of the sample); moderate decrease in use (15 percent of the sample); gradual decrease in use (35 percent of the sample); and no decrease in use (25 percent of the sample). The rapid decrease group averaged about 12 years to cessation of heroin use. Grella noted that this group had the highest rates of uptake of alcohol and other drug use after cessation of heroin use, which illustrates the challenge associated with the use of multiple substances in the context of defining recovery.

Grella also briefly discussed the What is Recovery? Study[29] (which was earlier discussed by Keith Humphreys and Alexandre Laudet). Grella noted that the main difference in this study's approach was the use of a sample that did not originate from a clinical setting, but rather from the general population, using an Internet recruiting method. The study's goal was to identify the domains and specific elements of recovery as experienced by people who defined themselves in various ways in relation to "recovery." Among the participants, 75 percent identified themselves as in recovery, 13 percent as recovered, 3 percent as in medication-assisted recovery, and 9 percent as having previously—but not currently—had a problem with alcohol and drugs. Grella noted the very small percentage of people who described themselves as in medication-assisted recovery, underscoring again that the views on this issue have not yet crystallized.

The study participants were asked to rate 47 items based on the extent to which they belong in a definition of recovery as they have experienced it. Factor analyses were then used to statistically reduce and group the 35 elements into four factors abstinence; spirituality; essentials of recovery; enhanced recovery. Latent class analysis derived five groups based on their adherence to items in each of the four factors: 12-step traditionalists (53 percent); 12-step enthusiasts (22 percent); secular class (11 percent); self-reliant class (11 percent); and atypical class (4 percent).[30]

Grella described the 12-step traditionalists as strongly abstinence oriented, with the majority indicating no use of alcohol or nonprescribed drugs. They had high rates of treatment participation, particularly in 12-step programs, and strongly endorsed spirituality; they tended to identify as in recovery. The 12-step enthusiasts mainly differed from the 12-step traditionalists by being less likely to indicate no use of nonprescribed drugs. The self-reliant class moderately endorsed abstinence from alcohol and illicit drugs and no abuse of prescription drugs. They had lower endorsements of items on the questionnaire pertaining to social interactions, which receive particular emphasis in 12-step programs, such as learning how to get support, helping others, giving back, being able to have relationships. Those in the secular class were generally younger, had spent fewer years in recovery, and more often identified as "used to have a problem." They had lower levels of endorsement of spirituality and were more tolerant of non-abstinence, with higher rates of alcohol use. They also had lower rates of 12-step participation. Grella noted that although this group was small (11 percent of the sample), they are an important group to pay attention to because they are younger and may be tapping into changing social trends, including changing definitions of recovery, and the fact that recovery options are more diversified than they used to be. Finally, the atypical class, the smallest group in this analysis, was characterized

[29]Kaskutas, L.A., Borkman, T.J., Laudet, A., Ritter, L.A., Witbrodt, J., Subbaraman, M.S., Stunz, A., and Bond, J. (2014). Elements that define recovery: The experiential perspective. *Journal of Studies on Alcohol and Drugs*, 75, 999–1010.

[30]Witbrodt, J., Kaskutas, L.A., and Grella, C.E. (2015). How do recovery definitions distinguish recovering individuals? Five typologies. *Drug and Alcohol Dependence,* 148, 109-117.

by less endorsement of spirituality and abstinence and high intolerance for recovery being religious in nature. They strongly endorsed being able to enjoy life as fundamental to recovery.

In summary, Grella highlighted several considerations that emerge from the studies she described as important when deciding on a strategy for how to measure recovery from substance use. Recovery is both a process of change and a point-in-time status, which presents a measurement challenge. Longitudinal and cross-sectional designs can produce very different findings. The sampling frame deserves careful consideration, she noted, with the two main options being clinical samples and general population samples. There are some questions surrounding the criteria used for recovery: abstinence is the critical component in some studies, while others use a multicomponent measure. Grella pointed out that tolerating some non-abstinence and some looser definitions appears to be resonating with some study participants. Another important question is the role of an individual's own perspective on recovery. Many studies measure behavior and outcomes that a person may or may not identify with as the status that researchers are attempting to understand.

Wilson Compton (National Institutes of Health) noted that one difference that seems clear is considering recovery from substance use disorders and recovery from mental health disorders is that in the case of substance use it is possible to specify the date when one stopped using a drug or drinking alcohol. In contrast, mental illness symptoms tend to wax and wane, and it is not easy to think about the initiation of recovery. The question is whether it is possible to reconcile these differences to develop a unified approach or whether different measures are needed for substance use and mental disorders.

Steven Fry (SAMHSA) commented that it is important to keep in mind that in many cases substance use disorder and mental illness are co-occurring. He said that when he was hospitalized due to schizophrenia as an adolescent, he was introduced to the effects of chemicals on one's emotions. After he left the hospital and visited his brother in college, he found other chemicals and substances and began drinking. This ended when he became a father, but he said that co-occurrence is not uncommon.

Donna Hillman (SAMHSA) added that in addition to the issue of co-occurrence, it is important to remember that there are many commonalities between the process of recovery from substance use and mental disorders. There are similarities in the reduction of substance use and symptoms, and there are basic tenets that need to be present to support the recovery process in both cases.

Nora Cate Schaeffer (University of Wisconsin) asked whether the identity of being in recovery is applicable in the same way to recovery from mental illness disorders as it is to recovery from substance use. From a sociological perspective, adopting an identity requires the availability of certain kinds of social supports or social structures.

Mark Salzer (Temple University) commented that people in recovery are a heterogeneous group, with some actively engaged in the mental health system and some not engaged, some who identify with being in recovery or the recovery movement, some who identify with a "peer movement," and some who do not identify with any of these. There are also many overlaps in identities and the terminology that people use, which creates an interesting measurement challenge. He added that he was struck by the many similarities between the two related areas of recovery. In his experience working with people in recovery from mental disorders, they often talk about an event, change, or epiphany that took place in their lives that they consider the beginning of their recovery. This can be the case even if they continue to experience mental

health issues or are hospitalized again: in some sense they think about being in recovery the same way as those recovering from substance use disorders.

Graham Kalton (Westat) said that from a measurement perspective he finds it difficult to reconcile the point-in-time perspectives on recovery with the idea of recovery as a process. In addition, it appears that there are different views on remission and occasional use of drugs or alcohol. He also wondered whether there are any methodological concerns related to the approach that involves asking people whether they consider themselves to be in recovery because of the potential cultural differences in how this is viewed by different groups.

Grella clarified that in the NESARC, asymptomatic risk drinkers are described as in remission because they did not meet criteria for abuse or dependence, but they were showing problematic use. She added that the characteristics of this category are fairly technical. However, there was also discussion of abstinent versus non-abstinent recovery, which she agreed would require further study. She said that this is not typically the focus of dialogue in substance use recovery. The dialogue is more frequently centered around the extent to which abstinence a defining criterion. For example, how to characterize someone who is participating in a 12-step group meeting and not using heroin anymore, but is smoking marijuana occasionally or drinking alcohol?

Kim Mueser (Boston University) wondered whether the issue is that abstinence is how recovery is defined by those who are the strongest advocates of the concept of recovery. In other words, such organizations as Alcoholics Anonymous (AA) have been the strongest champions of the term recovery and their position is that there is no recovery without abstinence. Consequently, people who decrease their substance use or stop using in a way that presents a problem tend to not describe themselves as in recovery because that would not be in line with the AA view. In his view, Mueser said, some level of substance use that does not meet criteria should not necessarily present a problem in the context of the definition. Similarly, in the area of mental health, one could argue that to some extent symptoms of mental disorder are a part of normal human experience and that they have become over-pathologized.

Michael Dennis (Chestnut Health Systems) noted that from a clinical perspective, the DSM defines what level of symptom severity and duration meet criteria that define a condition. Remission means the absence of those symptoms for a period of time, and full remission means the absence of all symptoms. Under the DSM definition, addiction is not based on the amount or frequency of use, but rather the behavioral health consequences of that use. He argued that the reason there is a disconnect is because one part of the field focuses on substance use and the other part focuses on the clinical criteria for the disorder: there is overlap between the two, but they are not the same thing. Grella added that the meaning of the words in popular culture and the ideology are another dimension that further contributes to the disconnect.

Dean Kilpatrick (Medical University of South Carolina) commented that there are also relevant differences between a harm reduction model and an abstinence model. In other words, if somebody used to be drinking two quarts a day and now is s drinking only one pint a day, some would describe that as a lot of improvement, while others would say that is very problematic.

THE MEANING OF RECOVERY FOR THOSE WHO SELF-IDENTIFY AS "IN RECOVERY" FROM SUBSTANCE USE

Laudet provided an overview of what is known from research studies she has worked on about how people in recovery from substance use think of the concept of being in recovery. The first two studies discussed by Laudet were both conducted in New York City and funded by the National Institute on Drug Abuse. One of the studies was a community-based study of 354 people recruited through ads and flyers and followed for 3 years.[31] The goal of this study was to elucidate patterns and psychosocial predictors of stable abstinence. Laudet noted that she considers it important that recovery studies not be limited to treatment-based samples because recovery is not limited to treatment contexts. The second New York City study involved 250 individuals who were recruited from two 12-step programs after entering outpatient treatment and followed for 1 year. The goal of this study was to identify predictors, patterns, and outcomes of participation in 12-step programs.

The third study discussed by Laudet was the Life in Recovery study, which was commissioned by the Faces & Voices of Recovery organization in 2012. The study was a web-based nationwide study which recruited 3,208 participants. As others have mentioned, she said, recovery from substance use is more than abstinence and supporting individuals in recovery involves more than supporting abstinence. One goal of this study was to document experiences at successive stages of recovery to identify service needs for a recovery-oriented system of care. Another goal was to document the perceived benefits of sustained recovery to individuals and to the nation.

One question that was examined by the community-based New York City study was why substance users quit using. Laudet said that the findings showed that people seek recovery primarily because they want a better life. Over 90 percent of the respondents in the study provided such answers as: didn't like where life was going or feared consequences; desired a better life; and was tired of the drug life. Participants were also asked what were their current priorities in life. The most important priority was "recovery work," in other words, staying clean, followed by employment. Mueser noted that this is an interesting difference between substance use and mental health recovery, because "recovery work" as a concept would not come up in the context of mental health.

Laudet and her colleagues also asked the sample entering outpatient treatment about priorities and found that staying clean and employment were also the main priorities for this sample, which was at an earlier stage in the recovery process.[32] She argued that learning about priorities is important because the main goal of recovery support services should be to help people reach their goals, assuming that these goals are good for the community and society.

Another question examined by the researchers was whether recovery leads to a better life. They asked study participants to talk about what, if anything, is good about being in recovery. The most frequently mentioned responses were in the categories of a new life; a second chance; a drug-free, clear head; and self-improvement.

[31]For details, see: Laudet, A.B. (2007). What does recovery mean to you? Lessons from the recovery experience for research and practice. *Journal of Substance Abuse Treatment,* 33(3), 243–256.

[32]Laudet, A.B., and White, W. (2010). What are your priorities right now? Identifying service needs across recovery stages to inform service development. *Journal of Substance Abuse Treatment,* 38(1), 51-9.

Laudet said that the community-based New York City study also evaluated stress and quality-of-life satisfaction as a function of abstinence duration.[33] These factors are important because stress is one of the main predictors of relapse. The study found that stress decreases significantly as a function of the duration of one's recovery from drug and alcohol problems. Quality of life appeared to continue to grow until about 3 years after the beginning of abstinence.

Findings from the Life in Recovery[34] survey showed that the rates of positive experiences increase as recovery progresses. The improvements include experiences related to family and social life, such as participating in family activities, volunteering, and voting. They also include health-related improvements, such as healthy nutrition, exercise, and medical care. Conversely, the rates of negative experiences decrease as recovery progresses. Laudet said that the findings from the Life in Recovery study underscore what Hillman had noted earlier--that positive experiences not only increase drastically from active addiction to recovery, but they continue to increase over the years.

Participants in the New York City community based study were also asked directly, in an open-ended format, how they would define recovery from drug and alcohol use.[35] Laudet agreed with previous speakers who pointed out that in its current form the SAMHSA definition is too broad and so would be difficult to measure. In this study, a better life or new life was the most frequently mentioned response regarding the meaning of recovery (44 percent), followed by total abstinence (41 percent). Other categories of responses mentioned were a life-long process (21 percent) and dealing with issues (17 percent). Laudet said that these responses illustrate that recovery from substance use is a multidimensional concept, which includes improvements in the areas of life that had been impaired by active substance use, as well as sobriety or reduced substance use.

A related concept discussed by Laudet was quality-of-life satisfaction, which she argued can help sustain recovery. Her research has found that baseline quality-of-life satisfaction predicted sustained abstinence 1 and 2 years later. For outpatient clients, quality-of-life satisfaction at the end of treatment predicted level of commitment to abstinence, which has been found in other studies to predict actual abstinence.[36]

Mueser remarked that the association between abstinence and improvements in various life domains makes sense. However, it is important to remember that many people have co-occurring substance use and mental health disorders, and for these people improvements are less likely to automatically happen when they stop using. Mueser argued that this is why it is important to be able to provide psychosocial rehabilitation to help people get back to work and improve the quality of their relationships, not just when they become abstinent but in order to foster that abstinence over the long run. Hortensia Amaro (University of Southern California)

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[33]Laudet A.B., Morgen, K., and White, W.L. (2006) The role of social supports, spirituality, religiousness, life meaning and affiliation with 12-Step fellowships in quality of life satisfaction among individuals in recovery from alcohol and drug problems. *Alcohol Treatment Quarterly,* 24(1–2), 33–73.

[34]See: http://www.facesandvoicesofrecovery.org/sites/default/files/resources/Life%20in%20Recovery%20Survey.compressed.pdf [May 2016].

[35]Laudet, A.B. (2007). What does recovery mean to you? Lessons from the recovery experience for research and practice. *Journal of Substance Abuse Treatment*, 33(Oct)(3), 243-256.

[36]Laudet, A.B., Becker, J.B., White, W.L. (2009). Don't wanna go through that madness no more: Quality of life satisfaction as predictor of sustained remission from illicit drug misuse. *Substance Use & Misuse.* 44(2):227–252.; Laudet, A., and Stanick, V. (2010) Predictors of motivation for abstinence at the end of outpatient substance abuse treatment. *Journal of Substance Abuse Treatment.* 38(4), 317–327.

commented that this is a special concern in the case of people with a history of trauma. She said that her work with women who have a history of trauma indicates that there are often new symptoms that emerge when the person stops using drugs or alcohol. She argued that treatment has to factor in this phenomenon and provide the tools and context necessary to prevent relapse.

Peter Gaumond (Office of National Drug Control Policy) agreed that in some cases abstinence can result in diminished quality of life. He suggested that the best way to think about it is as a tool for achieving recovery because most people are not going to be able to achieve an improved quality of life if they have a serious substance use disorder. Hillman agreed and added that in her view abstinence is very important during the initial stages of recovery, but at later stages it becomes a choice.

Salzer noted that Laudet's presentation focused on the increased participation in social life as a result of abstinence, and his work indicates that sometimes increased participation, such as returning to work or school, dating, or parenting, can also be a precursor to a decrease in symptoms in the mental health context. This outcome may also be true for substance use. In other words, the association between recovery and increased participation is likely bidirectional. He added that SAMHSA's definition captures this multifaceted aspect of recovery.

5

Defining and Operationalizing Recovery from Mental Disorders

This chapter summarizes a presentation by Kim Mueser (Boston University) on definitions of recovery from mental disorder and their implications for measurement and a presentation by Corey Keyes (Emory University) on the role of positive mental health in operationalizing recovery.

DEFINITIONS OF RECOVERY FROM MENTAL DISORDERS AND IMPLICATIONS FOR MEASUREMENT

Mueser discussed the definition and operationalization of recovery from mental disorder. As previous speakers indicated in the context of recovery from substance use, he noted, there are two main categories of definitions of recovery in the area of mental health. One category is the traditional medical definition, which is a below-threshold level of symptoms and the absence of significant associated impairment. The other category is personal definitions, which center primarily around the experience of recovery from mental illness. These definitions often allude to people's current appraisal of their mental illness, as well as their perceptions of changes in their mental illness. The definitions also reflect the importance to individuals of functioning well in such areas as social relationships, work, and self-care, regardless of symptoms.

An example of a broad personal definition is one developed by William Anthony: "Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness."[37] Mueser noted that this definition is largely subjective, although the notion of meaning and purpose implies behavior.

Mueser turned to one question that has been raised in the workshop: What are people recovering from? In the strictest sense, they are recovering from mental illness, but as other speakers have noted, mental illness has an impact on functioning and could lead to loss of self-worth, self-esteem, and self-efficacy, which also require recovery by those who are affected.

Some people are also recovering from trauma, which could include the traumatic effects of psychiatric symptoms, traumatic reactions to coercive treatments, and posttraumatic stress disorder (PTSD) symptoms. Mueser said that he and his colleagues conducted two studies that looked at what percentage of first-episode psychosis patients and multi-episode hospital patients met the symptom criteria for PTSD related to either symptoms or coercive treatment: in both studies, the number was around 60 percent. A somewhat larger number of people reported that the symptoms themselves were the most terrifying, but many indicated coercive treatment experiences. Some people reported that both of these experiences were traumatic. In addition to PTSD-related to mental illness, it is well understood that traumatic events in general increase

[37] Antony, W.A. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal,* 16(4), 11–23.

vulnerability to psychiatric disorders. In other words, Mueser said, it is also important to remember that some people have comorbid PTSD.

A second definition of recovery from mental disorder discussed by Mueser was one proposed by Patricia Deegan:[38]

> Recovery is a process, a way of life, an attitude, and a way of approaching the day's challenges. It is not a perfectly linear process. At times our course is erratic and we falter, slide back, regroup, and start again. The need is to reestablish a new and valued sense of integrity and purpose within and beyond the limits of the disability; the inspiration is to live, work, and love in a community in which one makes a significant contribution.

Mueser noted that this definition is quite nuanced and includes many dimensions of the subjective experience. The definition also focuses on functional outcomes and identifies different areas of functioning as priorities.

One of the challenges for measuring recovery from mental disorder is being able to identify areas of convergence between the medical definitions and the personal definitions of recovery. Mueser argued that several objective measures of psychosocial functioning (such as social functioning, work, school, and independent living) are related to both the medical and personal definitions of recovery. There is some evidence that more severe symptoms, especially depression and psychotic symptoms, tend to be associated with lower well-being, self-esteem, and self-efficacy. There is also some evidence that indicates that better psychosocial functioning is related to higher subjective well-being and related constructs. For example, when people with serious mental illness obtain competitive work, there is often a modest increase in their self-esteem and self-efficacy, and there are reduced mood symptoms.

Mueser said that although combining the objective and subjective definitions of recovery from mental disorder is challenging, one option is to define recovery in terms of psychosocial functioning, which is the area of greatest overlap in definitions. This in turn can lead to the development of models that integrate symptoms, objective functioning, and subjective experience.

Mueser described a treatment model that he and his colleagues developed as part of the NAVIGATE Program, which is a comprehensive, coordinated specialty program designed for people experiencing a first episode of psychosis. In this program, recovery is defined as functioning in the social and leisure domains, a broadly conceptualized sense of well-being, and role functioning. Figure 5-1 shows how this conceptualization of recovery interacts with different dimensions of the illness in this model.

The different dimensions of the illness (such as psychosis, negative symptoms, depression, cognitive impairment, substance abuse) can hinder recovery, but Mueser said that one can design interventions that specifically target these dimensions, such as medication or training in illness self-management. Other interventions can target recovery outcomes directly by providing support or teaching skills, and things like that or rehabilitation-based interventions. Figure 5-1 illustrates that it is possible to integrate the different dimensions of recovery into an overall treatment model.

[38]Deegan, P.E. (1988). Recovery: The lived experience of rehabilitation. *Psychosocial Rehabilitation Journal,* 9(4), 11-19.

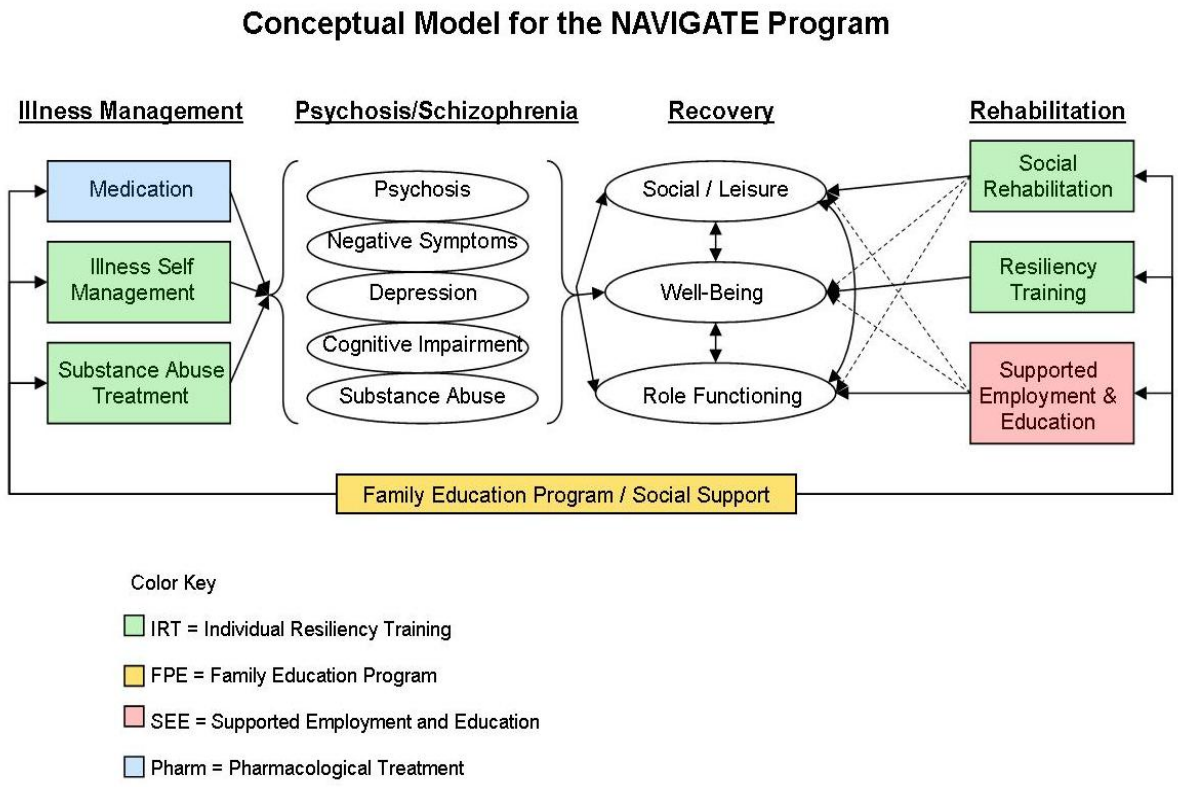

FIGURE 5-1 Conceptual model for the NAVIGATE program
SOURCE: The NAVIGATE Team Members' Guide. Available: https://raiseetp.org/studymanuals/Team%20Guide%20Manual.pdf [May 2016].

Mueser pointed out that there are nonetheless limitations to the convergence. First, recovery is nonlinear in nature. Recovery in one area of psychosocial functioning tends to be only very weakly correlated with recovery in other areas. In general, psychosocial treatment effects tend to be domain specific, with minimal impact on other areas of functioning. In other words, interventions that improve functioning in a work context tend to improve functioning only in that area and not generalize to other areas. For example, people can be going to work, but continue to have a very poor social life, which makes it difficult to develop a single definition of functional recovery. In addition, there is only a modest relationship between symptom severity and functional outcomes (e.g., between relationship between cognition, psychiatric symptoms, and work).

Mueser noted that there are difficulties associated with mapping some aspects of subjective experience (such as self-determination, hope) onto objective indicators of functioning. A somewhat related point is that associations between psychosocial functioning and subjective evaluations are much stronger in the case of people with mood disorders than people with schizophrenia-spectrum disorders. Reality distortion may influence one's ability to accurately perceive the quality of one's own functioning. Mueser noted that in schizophrenia-spectrum disorders, good insight is a well-known predictor of better psychosocial functioning over time. However, insight in the case of schizophrenia is also related to worse mood and worse subjective experience. The likely reason for this is that when people are asked to rate their own

psychosocial functioning, they are really being asked to compare themselves to other people, and those who have a lot of reality distortion do not see the discrepancy, which could lead to negative emotions. At the same time, Mueser said, being able to see the discrepancy can serve as the fuel for participation in recovery-oriented programs.

These issues illustrate that the nature of recovery reflects the heterogeneity in the impact of mental illness on people's lives, as well as in the process of improvement. Mueser argued that there is no single objective or subjective definition that is going to be sufficient to encompass the entire concept of recovery. Consequently, there is a question of whether objective and subjective recovery can be connected on the personal level. Mueser noted that there are different dimensions of recovery that are important to characterize in order to understand the relationships. He argued that there is value in maintaining a broad distinction between objective and subjective aspects of recovery and proposed the conceptualization of a "recovery profile" aimed at measuring multiple critical dimensions of recovery. This notion is similar to the multidimensional conceptualization of recovery mentioned by others, which can accommodate both objective and subjective aspects of recovery.

Mueser listed both the objective and subjective dimensions of recovery that he argued would need to be included in a recovery profile: see Box 5-1. The objective dimensions include various aspects of role functioning, mental and physical health, independent living, and social functioning. Mueser said that all of these dimensions can be measured. A list of subjective dimensions he tentatively proposed include aspects of well-being, sense of purpose, and internal and external processes related to mental illness. He noted that the internal processes related to mental illness are the processes that a person goes through within themselves, while what he labeled external processes are in fact active strategies that a person may be using in order to manage the mental illness.

To explore the potential relationships between objective and subjective dimensions of recovery and the utility of thinking in terms of a recovery profile that includes both dimensions, Mueser used the examples of sense of purpose and role functioning. Sense of purpose is related to what one does, such as work, school, or parenting, but not enough is known about the connection between sense of purpose and other subjective aspects of recovery. It is likely that improved role functioning enhances a person's sense of purpose, but this likelihood raises the question of the effects of creating new valued roles for a person with mental illness on her or his sense of purpose and other aspects of both subjective and objective recovery.

In terms of the implications for measurement, Mueser argued that there are both objective and subjective dimensions of recovery that do not map to one another. Moreover, the different aspects of these dimensions are also not highly correlated, so that it is not possible to create a single measure of recovery. A recovery profile that includes both objective and subjective dimensions presents a possible solution. The multiple measures of each dimension already exist, but there is no systematic approach to collecting or combining information or for interpreting the scores. In addition, he said, it is doubtful that it would be feasible to collect all relevant information by combining existing instruments because of the participant and research burden. Relying on existing measures could also be problematic if some of the measures are taken out of context.

BOX 5-1

RECOVERY PROFILE: OBJECTIVE AND SUBJECTIVE DIMENSIONS OF RECOVERY

Objective Dimensions

Role functioning
- Work
- School
- Parenting

Health
- Mental health (symptoms)
- Physical health

Independent living
- Stable housing
- Independence
- Self-care

Social functioning
- Friends
- Family
- Leisure

Subjective Dimensions

Well-being
- Hope
- Confidence
- Self-determination

Sense of purpose

Internal processes related to mental illness
- Acceptance
- Empowerment
- Resiliency
- Self-stigma (absence of)

External processes related to mental illness
- Proactive coping
- Illness self-management
- Personal medicine

SOURCE: Workshop presentation by Kim Mueser, February 2016.

Mueser argued that developing a new instrument would be useful to measure the recovery profile. A systematic approach with a single instrument would have the advantage of facilitating research, and it could also become a potential tool for individual treatment planning and the review of progress towards goals. He noted that the field of serious mental illness has been in need of such a standardized outcome measure for the last 30 years.

Corey Keyes (Emory University) commented that a particularly useful feature of a new instrument of this type could be to provide participants with the results of the survey after the interview. People in recovery could benefit substantially from receiving that information from researchers.

Grella noted the emphasis on hope and empowerment that characterizes discussions around recovery from mental illness, in contrast with the 12-step approach in the area of substance use recovery, in which one has to admit powerlessness. She noted, however, that there

are some distinctions embedded in the terminology that have to do with the different orientations historically of treatment across those two domains.

Mueser agreed that in a sense the concepts of recovery are almost diametrically opposed in the two areas. Recovery in substance use disorders means that one can have a life as long as they stop using substances, while the concept of recovery in mental illness is that one can have a life even if they continue to experience symptoms. The difference, Mueser said, is that there is a perception of greater control over substance use than mental health symptoms. In addition, in the area of mental illness, the emphasis of hope is partly aimed at countering the negative messages that psychiatry has communicated over the years about major mental illnesses, such as telling people with schizophrenia that they will never be able to work.

Laudet pointed out that another difference between the two areas is that drug use is illegal, which has led to the perception that a person is either using and is a criminal or is not using and then can be put "back into the fold." Mueser added that the issue of stigma surrounding mental illness is another consideration. There is a perception to some extent that as long as a person with a prior drinking problem is not drinking, he or she can do anything and can be trusted. But the stigma associated with admitting to having had a mental illness or mental health treatment is much more difficult to overcome, even if it happened 20 years ago.

Hortensia Amaro (University of Southern California) noted that there is discussion of the role self-initiated and self-directed trajectories in both substance use and mental illness recovery. However, some treatment is imposed, and the treatment process is also fairly directive. She wondered how the focus on self-agency in definitions of recovery can be reconciled with externally directed treatment situations in the context of measurement.

Mueser replied that for some mental health consumers, self-agency is critical in terms of getting into recovery and rebuilding their own lives. Because of that, the principle of respecting self-agency and capitalizing on it is important. However, the strength of a multidimensional definition of recovery is that it also reflects the fact that for many consumers recovery means a good place to live, good-quality social relationships, and work, and there are many ways to achieve those goals. In addition, as others have pointed out, there are many people who do not relate to the concept of recovery at all. Some may not relate to many of the subjective elements of recovery, but they are relatively satisfied with life and would score high on measures of the objective dimensions of recovery.

Kenneth Wells (University of California, Los Angeles) noted that there are several recent measures of recovery that are multidimensional. One example is the Maryland Recovery Measure, which includes questions on self-agency and self-efficacy. These items do not appear to be strongly associated with direct functioning and clinical outcome measures when the data are analyzed; rather, they form their own distinct self-efficacy domain.

James Jackson (University of Michigan) asked what the criteria would be for determining, in a general population survey, who would be asked questions about recovery. Mueser replied that he would focus on people who have some prior indicator of severe and persistent mental illness. He argued that including everyone who has had a psychiatric illness would be too broad, in part because most of what researchers know about the subjective aspects of recovery from mental disorders is from working with people with severe and persistent mental illness. Including a broader range of psychiatric illnesses could present a measurement challenge. In addition, the most underserved populations are people with severe and persistent mental illnesses, mainly schizophrenia spectrum and mood disorders with PTSD or co-occurring

substance disorders, and the impact of mental illness on their lives, as well as the disabilities they experience, are relatively more severe.

Jackson commented that Mueser's points suggest that to determine who should be asked about recovery, an impairment criteria could be applied, instead of specific diagnoses. This approach could be applied to both substance use and mental disorder. He added that one commonality between substance use and mental disorder that has not been discussed is that people with substance use problems often have cravings that could be described as conceptually similar to symptoms. In both cases, such a craving may be fine as long as the person is not acting on it. These types of commonalities are useful to consider as part of the discussion of a study design to measure recovery.

Wells said that although he understands the value of focusing on the severely ill population, there might be some advantages to a dual strategy. One strategy would be to develop a design targeted at understanding the issues associated with behavioral health resiliency and wellness for the general population. The other strategy would be focused on the subset of the population with severe mental illness and the specific issues relevant to them. This dual strategy would also help with providing some context for the data from those who are in recovery from severe mental illness.

THE ROLE OF POSITIVE MENTAL HEALTH IN OPERATIONALIZING RECOVERY

Keyes began his presentation by saying that health has traditionally been defined as the absence of illness or disease and that he is particularly passionate about trying to unpack mental health as more than the absence of mental illness. As part of his research, he looked back at the ancient Greeks, including Epicurus and Aristotle.

Keyes noted that happiness is one of six basic emotions that are all adaptive and functional in their own way but can become a problem when they persist for too long and in a way that is too strong. The function of happiness is to help people encode and memorize things that are good for us. This system can get hijacked by addiction and other problems, but positive mental health must consist of happiness.

Epicurus' philosophy was that a good life consists of pleasure or positive emotions, and generally the avoidance of unnecessary pain. Keyes said that this interpretation of happiness focuses on emotional well-being. Accordingly, one approach to measuring happiness involves items from the Mental Health Continuum Short Form, which asks people to think about the past month, and using a scale from never to every day, to say: how often they felt happy; how often they felt satisfied with life; and how often they felt interested in life.

Keyes said that another tradition of happiness originates from Aristotle, who said that happiness is not first and foremost about feeling good, but about excellence and about functioning well in life. He and his colleagues operationalized this interpretation in two ways: as psychological well-being and as social well-being.

Psychological well-being includes: self-acceptance; positive relations with others; personal growth; purpose in life; environmental mastery; and autonomy. Keyes said that these items were part of a list that was developed by social psychologists in the 1940s to inform the work of the National Institute of Mental Health (NIMH). He noted that positive mental health was part of the discussion when NIMH was created but is only now receiving serious attention.

To measure happiness, operationalized as psychological well-being, Keyes and his colleagues asked study participants to think about the past month and answer such questions as whether they: liked most parts of their personalities; had warm trusting relationships with other people; were being challenged to become a better person; felt that their lives had direction and meaning; were able to manage their lives; and were confident that they could express their own ideas and opinions.

The social well-being operationalization of happiness includes: social acceptance; social integration; social contribution; social coherence; and social growth. To measure these dimensions, Keyes and his colleagues asked people questions about whether they: trust and like other people; belong to a community in which they derive a sense of comfort and joy; feel that what they do on a daily basis contributes value and worth to the world; are able to make sense of what is going on around them in their social groups, institutions, or society; and are being challenged as a member of units, families, teams, and in workplaces to become a better person.

Keyes said that despite a tradition focused on positive feeling and positive functioning, when researchers began studying well-being, the emphasis was on depression. In public health today, there is a lot of talk about well-being and health and the need for a mentally healthy population, but what is studied is mental illness. He noted that the concept of flourishing turns the diagnosis of depression on its head, referring to the presence of good mental health.

Keyes said that to be diagnosed as flourishing one has to have had, every day or almost every day in the past month, 6 of any of the 11 positive functioning characteristics that he listed as being part of psychological and social well-being, combined with at least 1 of the 3 emotional well-being items. In other words, 7 out of 14 items are required based on the definition. He noted that the distinction between functioning and feeling is a very important one.

Keyes said that the factor structure in this approach has been replicated not only for adults, but also for adolescents aged 12 and older and in populations outside of the United States. Item response theory analysis shows that there is no differential item function in the 14 items by race, gender, or by disease function over time. There is also no differential item function cross-culturally.

The hypothesis behind a two-continua model—of mental health and mental illness—is that mental health is more than the absence of mental illness. One of the continua is that of mental illness, from low mental illness to high mental illness. This is the continuum that has traditionally received the most interest. However, Keyes argued, a second continuum from low mental health to high mental health also needs attention. This continuum measures the presence and absence of emotional, psychological, and social well-being.

Keyes said that studying the mental health continuum is important because the absence of mental illness does not mean that a person is flourishing. In fact, studies indicate that the vast majority of the population is not flourishing. This finding represents a large burden to populations, but the problem appears to remain invisible to public health because one has to become diagnosed with a disorder in order to be treated.

Another point of the two-continua model Keyes highlighted is that just because one has a mental disorder, or had a mental disorder in the recent past, does not mean that the person does not have some level of well-being. Of course flourishing with mental illness is quite rare, but it does happen. The most common occurrence is that people who have mental illness have moderate mental health, and it is rare that people are languishing, which would be the complete absence of mental health combined with mental illness.

Data show that level of mental health determines how well people function with a mental disorder. Keyes argued that recovery is not just about being symptom free, but rather a movement towards flourishing. Stated another way, any movement towards flourishing is a movement towards recovery.

Keyes said that flourishing is not just an artifact of people's minds. He and his colleagues have been studying the genetics of positive mental health along with the mental illness, based on a nationally representative sample of adult twins. Using these data, the best-fitting model indicates that the three types of well-being (emotional, psychological and social) have a single genetic source, and it is 72 percent heritable. There were no differences observed in the model between men and women.

The data also show that less than one-half of the genetic variance for mental disorders, such as depression, is shared with the genetic variance for flourishing. This finding means that one can inherit a high risk for depression, but can also inherit a high genetic propensity for flourishing. However, being free of a genetic propensity for depression does not mean being free of a risk of poor mental health, if one inherits a low genetic propensity for flourishing.

Keyes discussed several studies that illustrate implications of the two-continua model. One was the Healthy Minds Study, a survey of university students.[39] Using the Patient Health Questionnaire, approximately 13 percent of respondents screened positive for a mental disorder, such as depression, panic attacks, or generalized anxiety. The total included 3 percent of students who were flourishing, 8 percent who had moderate mental health, and 2 percent who were languishing. In other words, the data showed that the presence of mental illness does not mean the complete absence of mental health. The data also showed that the absence of mental illness does not necessarily mean flourishing. The researchers found that less than half of the students had good mental health, and 39 percent were not flourishing, which Keyes pointed out is worse than what one would observe in the general adult population. He argued that the problem is twofold: the rates of mental illness are too high, and the rates of mental health are too low.

Keyes said that another implication of the two-continua model is that, with or without a mental disorder, anything less than flourishing can result in serious problems. The second study he described was one conducted by researchers at the Mayo Clinic who studied medical student well-being.[40] The study followed more than 3,000 students at seven medical schools from their first through their fourth year. The study found that serious thoughts of dropping out and prevalence of suicidal ideation increased as mental health decreased from flourishing, to moderate, to languishing.

Another implication of the two-continua model is that the absence of flourishing can be as bad as the presence of mental illness. Keyes described the Midlife in the United States Study, which was based on a nationally representative sample of the U.S. population and included several follow-up surveys.[41] The study found that depressed adult miss an average of nearly 23 days of work annually. Those who were free of diagnosis in the past year but were not flourishing missed 5-1/2 days annually, while those who were free of diagnosis and were flourishing missed 2 days. When the number of days are multiplied by the number of people in

[39]See: http://healthymindsnetwork.org/hms [June 2016].

[40]Liselotte, N.D., Harper, W., Moutier, C., Durning, S.J., Power, D.V., Massie, F.S., Eacker, A., Thomas, M.R., Satele, D., Sloan, J.A., and Shanafelt, T.D. (2012). A multi-institutional study exploring the impact of positive mental health on medical students' professionalism in an era of high burnout. *Academic Medicine* 87(8), 1024-1031.

[41]See: http://midus.wisc.edu/ [June 2016].

each category, it becomes clear that not flourishing is associated with more days missed annually than depression. Of 15,062 missed workdays, 5 percent were among those who were flourishing, 52 percent were among those who were free of mental disorder but not flourishing, and 43 percent were due to mental disorder, including depression, panic attacks, and generalized anxiety. In this study, respondents were also asked about days when they did not miss work but they were not able to perform all their duties, left early, as well as about medical visits for both physical and mental reasons, and the patterns were similar. In other words, in addition to mental illness, not flourishing is also a substantial problem, and in some cases can have a bigger impact on days missed and the number of medical visits than the presence of mental illness itself.

The final implication of the two-continua model discussed by Keyes was that health may be more serious than illness. In other words, health and its loss are in some ways more important than illness because data shows that it is the loss of good mental health that precede and elevate the risk of disorders such as depression, panic attacks, generalized anxiety. Data from the Midlife in the United States Study showed that in 1995, 18.5 percent of the adult population fit the criteria for one of those three mental disorders.[42] When the sample members were reinterviewed in 2005, 17.5 percent fit the criteria. The overall percentages did not change, however: 52 percent of the cases in 2005 were not cases in 1995. What the researchers found was that being free of mental disorder but not flourishing in 1995 created threefold to eightfold risk of having mental disorder in 2005, compared with the risk associated with flourishing. In other words, in comparison with being mentally healthy, anything less than flourishing results in elevated risk of developing mental illness.

Another study discussed by Keyes collected data from medical interns every 3 months over the course of 1 year.[43] The researchers found that changes in flourishing, using the measure developed by Keyes, preceded elevations of the risk of depression.

A study of a representative sample of Dutch adults, which also involved four data collections over time, found reciprocal causal connections between positive mental health and mental illness.[44] In other words, recovery and treatment for mental illness results in improvements in good mental health, while losses of good mental health increase subsequent risk of psychopathology.

Keyes said that the recovery goal is complete recovery, and in recovery a person is flourishing. However, when one has a mental disorder, any improvement in good mental health is a sign of movement towards recovery, and several recent studies have underscored this point.[45] He argued that measures of recovery should include some elements of flourishing. If flourishing can prevent the onset of mental illness, it is possible that it can also prevent relapse of mental disorders and substance use disorders; more studies would be needed to determine if this is so.

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[42]Keyes, C.L., Dhingra, S.S., and Simoes, E.J.(2010). Change in level of positive mental health as a predictor of future risk of mental illness. *American Journal of Public Health.* 100(12), 2366-2371.

[43]Grant, F., Guille, C., and Sen, S. (l2013). Well-Being and the risk of depression under stress. *PLoS One.* 8(7), e67395.

[44]Lamers, S.M.A., Westerhof , G.J., Glasb, C.A.W., and Bohlmeijera, E.T. (2015). The bidirectional relation between positive mental health and psychopathology in a longitudinal representative panel study. *The Journal of Positive Psychology.* 10(6), 1-8.

[45]See Fledderus, M., Bohlmeijer, E.T., Pieterse, M.E., and Schreurs, K.M. (2012). Acceptance and commitmenttherapy as guided self-help for psychological distress and positive mental health: A randomized controlled trial. *Psychological Medecine.* 42(3),485-495; McGaffin, B., Deane, F.P., Kelly, P.J., and Ciarrochi, J. (2015). Flourishing, languishing and moderate mental health: Prevalence and change in mental health during recovery from drug and alcohol problems. *Addiction Research and Theory.* 23(5), 351-360.

Steven Fry (SAMHSA) commented that the discussions have reflected a lot of agreement that recovery happens, is valid, is accepted, is multidimensional, and that there are many ways of getting there. Accordingly, there are also many different ways of measuring it. However, there is also prejudice, discrimination, and an unwillingness to intervene until there is a crisis. In addition, he noted, education in schools could equip people with a vocabulary about mental health emotional well-being. He said that he would like to see the vision of recovery described by Keyes widely disseminated to make it possible to detect and arrest mental illness at the earliest stages and to give people the tools to improve their quality of life.

Mark Salzer (Temple University) said that the role of flourishing underscores the importance of measuring these types of constructs among a broad range of people, in addition to those with serious mental illness. He said that one of his concerns is that recovery is a complicated concept and, as the discussions have illustrated, has a variety of definitions. He asked Keyes whether he thought that measuring flourishing could replace measuring recovery altogether.

Keyes answered that he would like to think that the field can mature and perhaps grow out of the concept of recovery, because it would shift the focus to facing something positive, not something that was left behind. However, he does not think that measuring recovery can be replaced now because research in these fields is in the early stages. Recovery from mental illness is an important goal, shared by many people. It is a rallying call and what helps them face life and its challenges with meaning. From a measurement perspective, Keyes said, it is important to remember that the two-continua model suggests that one can have a mental disorder and be moving towards recovery, but for others being free of mental disorder may never be possible though they may be moving towards flourishing.

Michael Dennis (Chestnut Health System) commented that ultimately what people want is a normal life, and that could mean not just having a job and a house, but also having well-being and having a sense of happiness. It has been argued through the workshop that recovery is a process, and if so, Dennis said, then measuring the values that one aims to achieve is the most straightforward approach, which can apply across both substance use and mental health and even other health conditions.

Kenneth Wells (University of California, Los Angeles) commented that as part of developing the Community Partners in Care Study that he discussed earlier (see Chapter 2), the researchers worked with people in the community to determine their main goals in recovering from depression, which was the focus of the study. The framing the respondents favored to describe what they wanted was mental wellness. Consequently, the researchers included in the study questionnaire items on happiness, peace of mind, and energy, which matched the words the respondents had used. In looking at the outcomes of the study, the largest effect of the intervention was on mental wellness. There also was an effect on distress, which is in line with the duality argument, but the largest effect was on what the participants valued the most. This outcome was particularly pronounced among Latino study participants. Another observation from the study, Wells noted, is that Latinos, especially men, do not like to say that they are depressed, but they are willing to say that they are not completely happy. In other words, capturing outcomes in a way that is meaningful to participants in a diverse population study is particularly challenging.

Benjamin Druss (Emory University) said that Mueser's presentation suggested that the objective measures of recovery are particularly relevant for those who are in recovery from serious mental illness. He wondered whether the functioning measures also fit into a continuum

model. Mueser said that they do, and he clarified that he considers functioning measures especially important for people with serious mental illness because they are more changeable than the underlying subjective aspects of recovery. However, he said, measuring positive mental health as described by Keyes would nonetheless be useful. He noted that flourishing seems subjective, but it is also more related to a person's day-to-day functioning than some of the other subjective aspects of recovery.

Hortensia Amaro (University of Southern California) summarized several themes that she said emerged from the discussions. One theme is that recovery is an ongoing process, and it involves engagement in and movement towards a set of aspirations. Another theme is that recovery is multidimensional, that one could be doing well in one area but not in another, that there are different factors that facilitate recovery, protective factors, and also risk factors, and that those can occur at the individual, family, and community levels. The concept of a recovery profile was noted by many speakers, as was the importance of capturing the objective and subjective dimensions of recovery. The notion of measuring flourishing adds another dimension to thinking about recovery.

6

Measures of Recovery

Two presentations at the workshop focused on existing measures of recovery. Alexandre Laudet (Center for the Study of Addictions and Recovery, National Development and Research Institutes, director emeritus) discussed existing measures of recovery from substance use. Mark Salzer (Temple University) discussed measures of recovery from mental disorder.

MEASURES OF RECOVERY FROM SUBSTANCE USE

Laudet began by saying that the discussions underscored that the great variety of definitions of recovery that have been developed. It is also clear that there are some common elements and overlap, both within the fields of substance use and mental illness but, also across the two fields.

Close attention to the methods used to measure recovery from substance use reveals, however, that most of the time the question that is used is simply about abstinence in a yes/no format. Furthermore, the question is often about abstinence from one specific substance, despite the fact that the use of multiple substances is typical among people with an addiction. Laudet said that this approach is widespread because it is practical. In addition, she noted, self-report questions usually refer to the past 30 days. Sometimes biological samples are collected, but unless the sample is hair, the data from the samples are limited to a shorter period of time. As discussed, another approach that has been used is to ask: Did you once have a problem with drugs and alcohol, but no longer do (see Chapter 2).

Research shows that the SAMHSA definition of recovery contains dimensions that are meaningful to people in recovery, scientists, clinicians, and other stakeholders. The definition is multidimensional and implies change, with the main elements of a reduced relationship with substance use (either abstinence or significant reduction) and improvement in a person's quality of life.

Recent research has measured substance use and people's changing level of functioning and showed that different dimensions of recovery do not progress at the same time, nor necessarily in the same direction.[46] For example, during the initial stages of recovery from substance use, mental health gets worse. For other dimensions, such as employment, there is gradual improvement. In the long term, there is improvement overall, across dimensions.

Laudet said she expects that it will become clear that it is not possible to measure recovery in a way that yields one number, because a single score cannot capture the construct adequately. If a prevalence estimate is needed, that will have to be based on more than just one question, such as whether the person is in recovery or not.

[46]Dennis, M.L., Foss, M.A., & Scott, C.K (2007). An eight-year perspective on the relationship between the duration of abstinence and other aspects of recovery. *Evaluation Review,* 31(6), 585-612.

Laudet described three measures of recovery from substance use disorder that were discussed in a prior review of measures she prepared for SAMHSA.[47] She noted that research on mental health recovery has a much longer tradition and there are more measures and instruments available for that area than for recovery from substance abuse.

The first measure she discussed was the Modular Survey, an initiative with the goal to identify and develop common indicators and measures of consumer perception of care. It has a set of 21 items that covered four domains: quality of services, perceived outcome improvement, connectedness, and commitment to change. However, Laudet pointed out, the majority of the people in recovery are likely not enrolled in services, so this set of questions is likely not suitable for SAMHSA's current purposes.

The second available measure Laudet discussed is the recovery capital measure which is focused on the quality and quantity of recovery capital.[48] This instrument contains 23 items and measures eight domains**:** reliance on religion; spirituality; recent sobriety; stable income; alcohol/drug-free environment; percent lifetime spent free from the effects of substance use; satisfaction with living situation; and amount of education and training. Laudet noted that recovery capital is an important concept, as was discussed by Grella (see Chapter 3), but the instrument measures aspects of what is needed to achieve recovery, not recovery itself.

The Client Assessment Inventory was the third measure discussed by Laudet.[49] This instrument was developed to measure clients' self-reports and staff evaluations of clients' progress in the therapeutic community environment. The instrument contains 14 items and measures four broad dimensions: developmental, socialization, psychological, and community membership**.**

Laudet said that one of the characteristics the three measures have in common is that they are all multidimensional. They are all broadly consistent with the discussions about what ought to be included in a recovery measure, whether for substance use disorder, mental disorder (or even chronic illness). However, none of these measures are truly recovery measures, and Laudet argued that dedicated measures of recovery from substance use disorder still do not exist.

She listed the following criteria as essential in her view for a recovery measure:

- Multidimensional;
- able to quantify change;
- has sound psychometric properties;
- brief to be feasible for repeated administration, especially in the context of "concurrent recovery monitoring;"[50] and
- applicable across populations in terms of gender, age, cultural background, recovery path, and recovery stage.

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[47]See: http://www.samhsa.gov/sites/default/files/partnersforrecovery/docs/Environmental_Recovery_Scan.pdf [June 2016].

[48]Sterling, R., Slusher, C., and Weinstein, S. (2008). Measuring recovery capital and determining its relationship to outcome in an alcohol dependent sample. *American Journal of Drug and Alcohol Abuse,*34(5), 603-10.

[49]Kressel, D., De Leon, G., Palij, M., and Rubin, G. (2000). Measuring client clinical progress in therapeutic community treatment. The therapeutic community Client Assessment Inventory, Client Assessment Summary, and Staff Assessment Summary. *Journal of Substance Abuse Treatment*. 19(3)(Oct), 267-272.

[50]McLellan A.T., McKay J.R., Forman R., Cacciola J., Kemp J. (2005). Reconsidering the evaluation of addiction treatment: from retrospective follow-up to concurrent recovery monitoring. *Addiction,* 100(4), 447-58.

Laudet said that although none of the measures she reviewed are suitable for SAMHSA's goals, there are several additional measures that should be mentioned in this context. One of these is the Client Outcome Measures for Discretionary Programs developed by SAMHSA as part of the Government Performance and Results Modernization Act. The goal of this measure is to assess and track client progress for the purposes of external accountability to program funders. The questions are administered at entry into treatment, at discharge, and 6 months after discharge. Domains include: substance use; family and living conditions; education, employment, and income; crime and criminal justice involvement; mental and physical health treatment and recovery; and social connectedness. Laudet said that although the instrument is only used in the context of service delivery, it does have many of the dimensions that have been discussed as relevant to substance use recovery, including the acknowledgement of the process of change. In other words, it may be possible to build on this measure.

Another measure that is available is the Addiction Severity Index (ASI),[51] which has the goal of assessing and measuring change in addiction severity. The domains covered in this scale include: employment; medical; psychiatric; family and social; alcohol and drug use; and legal status. Laudet said that this is one of the most well-known addiction measurements. This index is also primarily used in the context of services, but it contains relevant dimensions, and it would be possible to capitalize on this work.

Laudet said that an existing measure that could be particularly relevant is the World Health Organization Quality of Life Instrument (WHOQOL). This instrument has been discussed at several expert meetings and by people in recovery as a measure that might represent a good starting point for measuring important aspects of recovery. The U.N. Treatnet Group, for example, recommended that in the absence of a dedicated measure of addiction recovery, both the ASI and the WHOQOL be used to measure the following domains: 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 Betty Ford expert panel in 2007 recommended the use of the WHOQOL, along with a measure of sobriety. The WHOQOL was also the measure selected in Connecticut by a group of people in recovery as the instrument most relevant to their experiences and needs. Laudet noted that Connecticut was the first state to adopt a recovery-orientation in 1999, and the WHOQOL was subsequently included in the state's consumer survey.

Laudet noted that the original WHOQOL contains 100 items, but an abbreviated, psychometrically strong version, the WHOQOL BREF, is also available, and is typically the one that is used. The scale yields four scores in four domains, and there is an additional overall quality of life question. The four dimensions measured by the WHOQOL BREF are as follows:

- physical (pain, energy, sleep, mobility, activities, medication, work);
- psychological (positive feelings, cognitions, self-esteem; body image, negative feelings, spirituality);
- social relationships (personal relations, social support, sex); and

[51]McLellan A.T., Kushner H., Metzger D., Peters R., Smith I., Grissom G., Pettinati H., Argeriou M. (1992). The Fifth Edition of the Addiction Severity Index. *Journal of Substance Abuse Treatment*, 9(3), 199-213.

- environment (safety and security, home environment, finance, health and social care, information, leisure, physical environment, transport).

Laudet summarized the advantages of the WHOQOL BREF:

- is in the public domain
- capitalizes on decades of field work
- cross-culturally validated in 15 centers worldwide
- strong psychometrics
- assesses domains that are highly relevant to recovery
- assesses both positive and negative aspects of life, objective and subjective ratings
- published norms for well and ill persons
- relatively short—the 26 items require 20 minutes to administer or 15 minutes to self-administer
- developed to be broadly applicable across disorder types, varying severity of illness, and diverse socioeconomic and cultural subgroups
- serves as a precedent for methods to develop supplemental population-specific or disorder-specific modules to best capture relevant dimensions for a given group

Laudet noted that the World Health Organization defines quality of life as being close to one's expectation of an ideal in one's own context. In other words, the expectations may be different depending on whether the person is an 85-year-old with arthritis or a 32-year-old athlete who just had a bad accident. This is another way of looking at objective and subjective aspects of recovery. The WHOQOL BREF also recognizes that while there are general similarities across groups, people dealing with specific situations or conditions may have certain needs and preoccupations that are not captured by an overall quality-of-life instrument.

The supplemental modules are designed to address those issues. For example, there are modules for HIV-positive individuals and individuals living with chronic pain. Laudet added that there was discussion at the Betty Ford meeting about also developing a module specific to recovery from substance use. She argued that the WHOQOL BREF along with a substance use recovery specific module might be the most suitable avenue to explore as a psychometrically strong measure of recovery.

One of the questions raised by SAMHSA was whether remission from symptoms should be included in the agency's working definition of recovery. Laudet said that she thinks that remission should be included because from the work she has done with people in recovery it is clear that their definition of recovery does include their relationship with substance use. Abstinence is only a means to an end, but it tends to be regarded by people as a central element in their recovery experiences. For example, they will say that they have not used alcohol or a drug for a certain number of years.

A follow-up question on this point is how to operationalize remission if it is to be measured. It could be that one is using less than previously; one is being completely abstinent; or one is being completely abstinent from both drugs and alcohol. This is a complicated question and requires further thinking.

In conclusion, Laudet argued that quantifying the problem is not particularly difficult because one can produce estimates of the number of people who meet the *Diagnostic and*

Statistical Manual of Mental Disorders criteria for substance use, which could be done through the National Survey on Drug Use and Health (NSDUH). But quantifying the solution, that is, measuring recovery from a substance use disorder, is much more difficult because recovery is a process, and it is multidimensional. Laudet argued, however, that measuring recovery is not impossible if there is the will and the funds to do it. One option might be to add the WHOQOL BREF to the NSDUH, for example, because the NSDUH already has questions on the substance use part of the equation.

Laudet said that there are estimates of the percentage of people with a drug and alcohol problem, and these percentages do not fluctuate very significantly from year to year. It is likely that the percentage of people in recovery does not fluctuate very significantly either. To produce more precise estimates it will be important to first determine what the intended primary uses of the data will be. For example, is it to inform funding for services? If yes, for which target group: for those needing treatment or for those in recovery? The answer to these questions would inform decisions about how to develop scales that are concise and contain the most relevant dimensions. The answers could also help identify the target population for the questions: for example, all lifetime users, past year, or past month users; those identified as having a substance use disorder; or those who self-identify as being in recovery. Laudet said that there are a number of open questions at this stage, but it seems clear that to monitor, develop, and fund services there is a need for a multidimensional measure of change, not a single score.

Kenneth Wells (University of California, Los Angeles) commented that if adding a questions to an existing survey is the avenue to be pursued, it should be noted that some of the domains measured by the various instruments can produce data that would be useful to have about the population as a whole, not just people with a substance use or mental disorder. Some questions on these domains may already be included in some form in existing surveys, or, if not, questions from the instruments discussed could be adapted in a way that makes them applicable to the general population. This strategy could enable SAMHSA to obtain data on a larger number of relevant questions from an existing survey. Laudet noted that there would be some downsides to a decision that involved only using parts of a scale that has not been tested to be used as Wells suggested. Wells agreed that testing would need to be done.

Dean Kilpatrick (Medical University of South Carolina) added that if some of the measures are useful both for people in recovery and the general population, administering them to both could provide interesting information that can further inform the development of measures of recovery. Some of the studies discussed during the workshop illustrate that there might be variation in these measures among those who have not have any substance use or mental disorder.

Peter Gaumond (Office of National Drug Control Policy) commented on the question of whether to measure partial recovery or remission from a diagnosable substance use disorder, in other words cases when one continues to use a substance but no longer meets diagnostic criteria. He argued that in these cases it would still be important to know what the relationship is between a person's condition at that point and their quality of life. That information might also provide insight into whether it makes sense to describe people with those characteristics as in being in recovery or in some other way.

Christine Grella (University of California, Los Angeles) commented that if a scale such as the WHOQOL BREF were to be added to the NSDUH or another survey, it would be very useful to also have a targeted subsample that would receive the questions more than once, in the form of follow-up surveys. A longitudinal design would be particularly useful to answer

questions about the process of change. The subsample could also include oversamples of populations of specific interest, such as people who have used substances other than alcohol and marijuana. She added that one challenge in general population surveys is that such subgroups are a very small part of the population.

MEASURES OF RECOVERY FROM MENTAL DISORDER

Salzer began by saying that he is concerned about the large number of definitions of recovery that exist, particularly in the context of mental health. The definitions that have been discussed are only a subset of the range of definitions that are in use. He argued that research on recovery is further complicated by the lack of adequate emphasis on measurement issues and how measures map onto the many definitions. However, although there are limitations in the existing measures, there is a large number of instruments, and the list includes some potentially good measures that could be used for at least some of the subdomains of interest. He added that he believes that sometimes deconstructing scales and reusing them is justified, if these decisions can be supported with evidence.

In his discussion of several measures of recovery from mental disorder, Salzer said that in the category of measures that focus on recovery-oriented attitudes, beliefs, and knowledge, the most notable one is the Recovery Attitudes Questionnaire.[52] The measure has two factors: recovery is possible and needs faith; and recovery is difficult and differs among people.

Another category of recovery measures focuses on perceptions of the extent to which policies, programs, and practices create a recovery-promoting environment, and these are used in numerous states and systems. These measures include recovery-oriented systems indicators, which measure the extent to which people feel supported in the areas of: meaningful activities; basic material resources; peer support; choice; social relationships; formal service staff; formal services; and self or holism.[53] Another measure in this category is the Recovery Self-Assessment, which has four versions; it assesses the degree to which programs implement recovery-oriented services.[54] The measure has five factors: life goals; involvement; diversity of treatment options; choice; and individually tailored services. A "person in recovery" version of this instrument also exists, with 36 items.

Salzer said that the measures that are most in line with the focus of the discussion so far are the clinical measures and the consumer-focused or subjective measures or recovery. This distinction was proposed by Alan Bellack[55] and is similar, although not identical, to the perspective presented by Kim Mueser (see Chapter 4). Most of what is known about mental health recovery comes from studies that have used a clinical model. Some of these studies measure time out of the hospital or since last hospitalization. One study with a multidimensional

[52]Borkin, J.R., Steffen, J.J., Ensfield, L.B., Krzton, K., Wilder, K., and Yangarber, N. (2000). Recovery Attitudes Questionnaire: Development and evaluation. *Psychiatric Rehabilitation Journal*, 24, 95-102.

[53]Dumont, J.M., Ridgway, P., Onken, S.J., Dornan, D.H., and Ralph, R.O. (2005). *Recovery Oriented Systems Indicators Measure (ROSI).* Available: https://www.power2u.org/downloads/ROSI-Recovery%20Oriented%20Systems%20Indicators.pdf. [June 2016].

[54]O'Connell, M., Tondora, J., Croog, G., Evans, A., & Davidson, L. (2005). From rhetoric to routine: Assessing recovery-oriented practices in a state mental health and addiction system. *Psychiatric Rehabilitation Journal,* 28, 378-386.

[55]Bellack A.S. (2006). Scientific and consumer models of recovery in schizophrenia: concordance, contrasts, and implications. *Schizophrenia Bulletin,*32,432–442.

approach looked at a 2-year period of functioning within specified normal limits in the domains of symptomatology, participating in work or school, living independently, and maintaining social relationships.[56] Salzer noted that these approaches tend to be focused on fairly broad behaviors.

In terms of measures focused on the subjective experience of recovery, Salzer noted that there have been several reviews published. A review by Burgess and colleagues looked at how measures fit nine criteria: explicitly measures domains related to personal recovery; brief and easy to use (50 or fewer items); consumer perspective; quantitative; scientifically scrutinized; sound psychometric properties; applicable to Australian context; acceptable to consumers; and promotes dialogue between consumers and providers.[57] Salzer noted that although the review used applicability to the Australian context as a criterion, all of the measures are also applicable in the United States. Burgess and colleagues identified four measures that met all the criteria: the Recovery Assessment Scale (RAS), the Illness Management and Recovery Scales (IMR), Stages of Recovery Instrument (STORI), and the Recovery Process Inventory (RPI).

Another recent review of measures of recovery from mental disorder was conducted by Shanks and colleagues.[58] The focus of this review was on the fit with the time framework of recovery, and the authors defined recovery as connectedness, hope, identity, meaning, and empowerment. The measures identified in this review as best fitting the criteria specified by the authors included the four on the Burgess list, and an additional two the Maryland Assessment of Recovery (MARS) and the Questionnaire About the Process of Recovery (QPR).

Salzer provided a brief overview of each of the measures that were highlighted in the Shanks review. The IMR has 15 items that assess personal goals, knowledge of mental illness, involvement of significant others, impaired functioning, symptoms, stress, coping, relapse prevention, hospitalization, medication, and use of drugs and alcohol.[59] The scale has no specific subscales. The MARS has 25 items, and a 12-item version is also available.[60] The scale measures six domains: self-direction or empowerment, holistic, nonlinear, strengths-based, responsibility, and hope. The QPR has 22 items with two subscales, for intrapersonal and interpersonal tasks associated with recovery.[61] The RPI has 22 items that measure six factors: anguish, connected to others, confidence and purpose, others' care or help, living situation, and hopeful or cares for self.[62]

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[56]Liberman, R.P., Kopelowicz, A., Ventura, J. and Gutkind, D. (2002). Operational criteria and factors related to recovery from Schizophrenia. *International Review of Psychiatry*, 14, 256–272.

[57]Burgess, P., Pirkis, J., Coombs, T., and Rosen, A.. (2011). Assessing the value of existing recovery measures for routine use in Australian mental health services. *Australian and New Zealand Journal of Psychiatry*, 45, 267–280.

[58]Shanks, V., Williams, J., Leamy, M., Bird, V.J., Le Boutillier, C., and Slade, M. (2013). Measures of personal recovery: A systematic review. *Psychiatric Services,* 64(10), 974-980.

[59]Salyers, M.P., Godfrey, J.L., Mueser, K.T., and Labriola, S. (2007). Measuring illness management outcomes: A psychometric study of clinician and consumer rating scales for illness self-management and recovery. *Community Mental Health Journal* 43, 459–480.

[60]Drapalski, A.L., Medoff, D., Unick, G.J., Velligan, D.L., Dixon, L.B., and Bellack, A.S. (2012). Assessing recovery of people with serious mental illness: Development of a new scale. *Psychiatric Services* 63, 48–53

[61]Neil, S., Kilbride, M., and Pitt, L, (2009). The Questionnaire About the Process of Recovery (QPR): A measurement tool developed in collaboration with service users. *Psychosis* 1, 145–155.

[62]Jerrell, J.M., Cousins, V.C., Roberts, K.M. (2006). Psychometrics of the Recovery Process Inventory. *Journal of Behavioral Health Services and Research,* 33, 464–473.

The RAS has three versions, with 41, 24, and 20 items.[63] The factors measured are personal confidence and hope, willingness to ask for help, goal and success orientation, reliance on others, and not being dominated by symptoms. Salzer noted that he particularly liked that the scale measures whether one's life continues to be dominated by symptoms because it reflects a view of recovery that focuses on living a satisfying and fulfilling life with or without the presence of mental illness symptoms.

Finally, the STORI has 50 items, with 30-item versions available: it measures five stages and four recovery processes.[64] The five stages are moratorium (a stage of hopelessness and self-protective withdrawal); awareness (the realization that recovery and a fulfilling life is possible; preparation (the search for personal resources and external sources of help; rebuilding (taking positive steps towards meaningful goals); growth (a sense of control over one's life and looking forward to the future). The four processes are hope; responsibility for wellness and control of life generally; establishing a positive identity; and finding meaning and purpose in life.

Salzer said that there are several psychometrically sound measures with some evidence of validity, and many of them have been informed by consumer perspectives on recovery. He pointed out, however, that the measures do not necessarily map onto the existing definitions of recovery. In addition, the construct of recovery that is being measured sometimes appears to be an amalgamation of other constructs, including constructs measured with already existing scales, such as quality-of-life measures and self-efficacy measures. He added that sensitivity to change also remains a concern for these measures. It is important to have a measure that is sensitive to change based on intervention and that can capture the process aspect of recovery. However, he noted, the existing measures do not typically have evidence of sensitivity to change.

In terms of SAMHSA's goals to measure recovery, one specific challenge raised by Salzer is that the agency has a definition with several associated components, as well as principles of recovery. These elements complicate the question of what is being measured. He argued that several of the principles could be measured with existing measures, or subscales, if measuring them is the goal. Those principles include hope; person driven; peer support; relational; strengths/responsibility; and respect.

Salzer said that some of the components of health, home, purpose and community in SAMHSA's definition can also be measured, although there are some operationalization challenges. For example, health could be operationalized as overcoming or managing one's disorders or symptoms. To measure this, it would be possible to use a symptom measure or to use the subscale of not being dominated by symptoms from the RAS. It would also be possible to look at whether a person is making informed, healthy choices that support physical and emotional well-being. Salzer said that these items could be measured by using the knowledge, relapse prevention planning, and medication taking items from the IMR, although he noted that some experts might disagree about whether the medication item belongs here. Other measures could include the personal responsibility items from the MARS and STORI scales (such items as "I work hard to find ways to cope with problems in my life"). Another option would be to use a healthy behavior checklist and just ask people how much are they smoking, are they taking care of their health, eating right, are they exercising, are they being active, and so on.

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[63]Corrigan, P.W., Giffort, D., Rashid, F., Leary, M., and Okeke, I. (1999) Recovery as a psychological construct. *Community Mental Health Journal,* 35, 231–239.

[64]Andresen, R., Oades, L., and Caputi, P. (2003). The experience of recovery from schizophrenia: towards an empirically-validated stage model. *Australian and New Zealand Journal of Psychiatry*, 37, 586–594.

There are fewer options for measuring the home component of SAMHSA's definition of recovery, which includes having a stable place to live and a safe place to live. Salzer said that one possibility to measure the safe home dimension could be the Kloos and Shah neighborhood safety measure.[65]

Another component in SAMHSA's definition is purpose, which Salzer said could be measured in several different ways. One option would be to use item #5 from the IMR: "How much time do you spend working, volunteering, being a student, being a parent, taking care of someone else or someone else's house or apartment? That is, how much time do you spend doing activities that are expected of you for or with another person? (This would not include self-care or personal home maintenance)." Another option would be to use the Temple University Community Participation Measure that asks about participation in 22 areas, importance of participation, and sufficiency.[66] The Community Participation Indicators is another measure that could be suitable.[67] This scale also measures various aspects of participation. Salzer noted that he likes the purpose component of SAMHSA's definition and particularly likes the idea of a community participation approach to measuring it because it reflects a focus on what happens to a person who is in recovery.

Finally, to measure community, Salzer said that a large number of measures exist that measure social network size, and aspects such as perceived social support.

Salzer said that if he had to develop a brief measure of recovery based on SAMHSA's definition, he would consider the following items:

1. "Coping with my mental illness is no longer the main focus of my life." (health, RAS item)
2. "I am making informed, healthy choices that support my physical and emotional wellbeing" (health)
3. "I can live in my current housing as long as I would like." (home)
4. "I feel safe in my current housing situation." (home)
5. "How much time do you spend working, volunteering, being a student, being a parent, taking care of someone else or someone else's house or apartment? That is, how much time do you spend doing activities that are expected of you for or with another person? (This would not include self-care or personal home maintenance.) (purpose, IMR item #5)
6. "I have people in my life who provide support, friendship, love, and hope." (community)

Salzer said that although mixing and matching items from various scales would be a controversial approach, he is pragmatic and realizes that a very lengthy interview may not be an option. Whether the use of the six items he proposed would work could be tested.

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[65]Kloos, B., and Shah, S. (2009). A social ecological approach to investigating relationships between housing and adaptive functioning for persons with serious mental illness. *American Journal of Community Psychology, 44,* 316-326.

[66]Salzer, M.S., Brusilovskiy, E., Prvu-Bettger, J., and Kottsieper, P. (2014). Measuring community participation of adults with psychiatric disabilities: Reliability of two Mmodes of data collection. *Rehabilitation Psychology*, 59 (2), 211-219.

[67]Heinemann, A. (2007). *Community Participation Indicators*. Available: http://www.ric.org/app/files/public/3598/CPI-commnity-participation.pdf [February 2016].

Kim Mueser (Boston University) clarified that the medication item on the IMR scale is framed in terms of whether people who have decided to take medication indeed take it as directed. If people choose not to take medication, it is not rated.

Amaro commented that the extent to which housing is under an individual's control varies by a person's place in the social hierarchy. Some of the characteristics of housing depend on local ordinances and policies and whether one has a criminal record. Segregation can also play a role in where a person lives. Exposure to drugs in one's community can act as a trigger and influence relapse. Amaro argued that some of the items that are conceptualized as individual-level factors are not individually determined for many people..

Salzer replied that the personal and environmental factors certainly interact, and he noted that one of his areas of research is looking at environmental factors as they influence recovery, well-being, and participation. Although it is true that the six questions he proposed would be administered in a vacuum, the current goal is to measure recovery, not to measure the determinants of recovery. He added that in some of his research measuring recovery among people with serious mental illness, he and his colleagues found that objective environmental influences, such as the amount of crime in the neighborhood, had very little influence on recovery. The team is now in the process of conducting follow-up studies that assess the subjective experience of these environmental factors.

Amaro asked Salzer to clarify what he sees as the issues with the measures' ability to capture change. She said that one issue she has come across in her use of the scales with people in treatment is that some of the questions are about change in circumstances that can take a long time to shift because of social barriers (e.g., housing, employment, education, involvement with the criminal justice system).

Salzer said that if sensitivity to change is interpreted as sensitivity to changes that a mental health or a substance use treatment program can generate, treatment can only have limited effects, especially for concepts for which there is a lot of environmental influence. However, if one were to look at services that address those environmental factors, such as supported housing programs, the influence of those factors might be better reflected in the measures.

Mueser said that the IMR is sensitive to change, but it is not a pure measure of recovery: it is a measure of illness self-management and recovery. Several studies have shown that the IMR program does change the movable factors that it targets.

Graham Kalton (Westat) said that he is still wrestling with the question of how to operationalize recovery. If someone who used to have no social contact moved towards slightly more social contact but still falls far short of what one would like to see, would that be considered recovery? He also noted that there was relatively little discussion about issues that may be specific to how these scales would work in surveys of the general population. Salzer agreed with Kalton that the main challenge is that recovery means different things to different people.

7

Data Collection Designs

SAMHSA'S RECOVERY MEASUREMENT PILOT STUDY

Alyson Essex (SAMHSA) said that SAMHSA's preliminary recovery measurement pilot study was designed as part of the agency's recovery support strategic initiative. The goal of the pilot was to test recovery measures for potential use with populations in SAMHSA's discretionary grants program. This effort is largely separate from the work conducted to expand the collection of data on recovery in the general population, but it is highly relevant.

Essex said that prior to her tenure at SAMHSA, there were discussions about the potential use of the World Health Organization Quality of Life Instrument (WHOQOL) BREF (see Chapter 5) in the pilot study. The concern was the length of the instrument. She said that after conversations with the World Health Organization, the idea of using a new tool called the WHOQOL-8 emerged. The WHOQOL-8 comprises four domains: physical health, psychological health, social relationships, and environment; this instrument was identified as best capturing the four dimensions of recovery that have been discussed: health, home, purpose, and community.

Preliminary work on the WHOQOL-8 has been done in 10 countries, and its scale demonstrates good psychometric properties. SAMHSA is the first group to be testing this tool with the U.S. population.

The WHOQOL-8 includes two questions on overall health: "How would you rate your quality of life?" "How satisfied are you with your health?" There are also two physical health questions: "Do you have enough energy for everyday life?" and "How satisfied are you with your ability to perform your daily activities?" There is one psychological question: "How satisfied are you with yourself?" There is one question on social relationships: "How satisfied are you with your personal relationships?" Finally, the scale contains two questions that measure the environment: "Have you enough money to meet your needs?" and "How satisfied are you with the conditions of your living space?"

Essex said that partly by using the WHOQOL-8, SAMHSA developed what the agency is calling a recovery measurement package. The package includes: the WHOQOL-8; Government Performance and Results Act (GPRA) measures on alcohol, drug use, and mental health recovery, which were decided based on a meeting with a workgroup; and one measure of empowerment.

The goal for the pilot study was to collect data from 300 clients in SAMHSA's discretionary grant programs and conduct psychometric testing. The initial design called for a longitudinal self-administered survey, and the plan was to collect the data as part of the standard GPRA data collection at intake and then follow up with another survey 6 months later. Essex said that despite several activities focused on promoting the study to grantee representatives, participation was lower than anticipated because the grantees were concerned about the

additional burden, on the staff and on clients, imposed by the study. As a result, SAMHSA decided to do only a one-time, baseline data collection, instead of the longitudinal study that had been intended.

The data collection was fielded between February and July of 2015, at 14 grantee sites with 171 individuals. The participants were involved in one of three SAMHSA grant programs that were focused on the areas of housing and recovery services for individuals experiencing chronic homelessness; expansion of infrastructure to integrate co-occurring and housing services; and integrated primary and behavioral health care for individuals with serious mental illness.

In terms of psychometric testing, Essex said that due to the small sample size the agency was not able to use advanced techniques, such as structural equation modeling or confirmatory factor analysis. Instead, SAMHSA used principal components analysis, which showed that the eight-item measure was a one dimension construct, as hypothesized. The scale had a coefficient alpha of 0.848, indicating a high degree of reliability.

SAMHSA also conducted psychometric testing for all 21 items that were included in the recovery measurement package, and the results provided conditional evidence that the items were measuring one underlying construct. Two items had loadings that were low enough to suggest that they were not strongly associated with the underlying construct: self-efficacy for managing one's health care needs and enrollment in a job or training program. The coefficient alpha for this scale was 0.745, which is in the acceptable range for scales in their early development.

Essex said that although the results were positive, the findings must be interpreted with caution, given the small sample size. She added that information gleaned from the survey provides a framework for a more robust study and analysis. SAMHSA is leaning towards support for use of the WHOQOL-8 with SAMHSA discretionary grantees, but additional testing will be needed for the 13 questions in the package. The agency is also considering customizing the tool for specific SAMHSA grantee populations and exploring the development of an adolescent recovery measure.

Kim Mueser (Boston University) commented that these types of scales can behave differently depending on a person's specific type of mental disorder. For example, people with schizophrenia spectrum disorders tend to self-rate themselves higher on functioning items than people with mood disorders, even though objective measures of the same individuals indicate that they are functioning somewhat lower. Because of these differences, if a pilot test does not include a sufficiently large sample of people with disorders such as schizophrenia, generalizability could be a concern.

Michael Dennis (Chestnut Health Systems) said that he and his colleagues also conducted psychometric testing for the WHOQOL-8, using a sample of 480 women being released from jail. The sample included women with both substance use and mental health issues, and about 10 percent had serious mental illness. The sample was followed for 3 years. Dennis said that the researchers observed differences that were similar to those Mueser described. However, the WHO-8 worked well within subjects.

Essex asked whether Dennis included questions other than the WHOQOL-8 in his study. Dennis said that he and his colleagues included the same questions that were in the original SAMHSA proposal. The additional questions increased the effect size. He added that the scale also worked well to distinguish people who are in the community with no use, abuse, or dependence.

Mueser noted that improvements in housing stability could have a big impact on the findings. He said that among people with severe mental illness, the biggest change in improvement in general life satisfaction is typically noticed when they go from being homeless, in jail, or in the hospital to stable housing in the community. Dennis said that he and his colleagues have not yet analyzed the data in a way that would allow them to look at this issue. Essex said that the SAMHSA sample included a large proportion of homeless populations, and there was an increase in the reliability of the 21-item tool when the home item was removed.

Alexandre Laudet (Center for the Study of Addictions and Recovery, National Development and Research Institutes, director emeritus) noted that the psychometric properties from the tests conducted in various countries look very strong. She said that she was hoping that this will work equally well in the context of addiction research. She recommended the use of the WHOQOL-BREF (see Chapter 5), but a shorter version would be much more practical to administer, and, along with the substance use items, this set could provide all of the data that are needed.

TRADEOFFS OF DIFFERENT DATA COLLECTION DESIGNS

Dennis began his discussion of tradeoffs of different data collection designs by describing some common data collection strategies for measuring recovery, including duration questions, multiple intervals or recency, event history, and repeated measures.

Duration Questions: One option for measuring recovery is to ask duration questions, which can provide data on: (1) the prevalence of various durations of abstinence or remission and (2) changes in the facets of recovery over the duration, which taps into the process idea. The main advantage of this approach is that it is very low burden. The disadvantage is that these types of questions can be subject to recall bias.

Multiple Intervals or Recency: Another strategy for measuring recovery is to collect data at multiple intervals or focused on recency. This approach provides data on: (1) the prevalence of various durations; (2) change in facets; (3) the number and pattern of episodes; and (4) trajectories and trends. The main advantages of this approach, Dennis said, are that it allows researchers to capture a clear, clinical definition of remission and that the respondent burden is only moderate. There is still a potential recall bias, and the data can only be combined in a limited number of ways, depending on how many periods are asked.

Event History: Event history involves asking questions that collect dates for key events, such as when did the abstinence begin, when did it end, when did the treatment begin, and when did it end. This approach can provide information on: (1) prevalence of various durations; (2) changes in facets; (3) the number and patterns of episodes; and (4) and trajectories and trends. The main advantage of this strategy, Dennis pointed out, is that the data obtained can be summarized in multiple ways: for example, researchers can create summary measures. This strategy, too, can be subject to recall bias, he noted. Another concern related to this strategy is that respondent burden increases with multiple measures.

Repeated Measures: Collecting data more than once prospectively is the most elaborate design option. It allows researchers to examine pattern of change within individuals and evaluate predictors of transition. This method has the lowest potential for recall bias, but a study of this type can be logistically more difficult to conduct.

Dennis noted two crosscutting issues with implications for study designs. One issue is the role of multi-morbidity, which is common: it can lead to specification errors when researchers study effects. He also argued that there is a great need to study service utilization and costs because services in these areas are underfunded, and it is important to demonstrate their value.

Dennis discussed the advantages and disadvantages of the National Survey on Drug Use in Health (NSDUH) as a vehicle for measuring recovery. One advantage of the NSDUH is that it is a very large cross-sectional sample by state planning districts. It measures prevalence, recency, and frequency of substance use. It also measures past-year substance use disorder symptoms by substance. In addition, the survey collects data on some symptoms of mood disorders and prior diagnosis related to mood or anxiety. The NSDUH also has several measures of past-year service utilization.

One of the disadvantages of the NSDUH as a potential vehicle for measuring recovery is that the current survey lacks data on duration of abstinence, multiple time periods, event history, or repeated measures for substance use or other mental disorders. Although some mental disorders have been measured periodically or as part of substudies linked to the NSDUH, the survey does not regularly collect data on internalizing disorders, such as anxiety, trauma, and suicide or externalizing disorders, such as attention disorder, hyperactivity, gambling, and impulse control. In addition, the NSDUH does not have any data on multi-morbidity, and quality of life is not measured. Finally, Dennis pointed out that the NSDUH's data on service utilization and costs could be more comprehensive.

Dennis also discussed the SAMHSA GPRA measures. He noted that there are separate measures for substance use and mental health. The substance use data for individuals served by grants are typically collected at intake, 6 months, and from patient records at discharge. The measures include detailed days of substance use by substance in the past month and days of mental health problems by symptoms. Self-reported data are also collected on past month days of service utilization in 12 areas: substance use, mental health, and physical health in outpatient, inpatient, and emergency department settings; days of medication; arrest and incarceration. Medical records data are collected for treatment episodes in over 40 areas. The GPRA measures also include a lifetime trauma symptom screener and past 30-day social connectedness measures. He commented that the fact that the self-report measures only refer to the past 30 days is a particularly problematic characteristic of these measures. Although data are obtained from patient records at discharge, the grantee records do not contain information on treatment or services received from other sources. He added that the GPRA data collection instrument for substance use is long and has many redundant items.

The schedule for the GPRA data collected about individuals served by mental health grants is similar to that of the GPRA data on substance use: information is obtained at intake, 6 months, and at discharge. The data collection includes past month Likert measures of functioning, substance use, depression and trauma symptoms, perception of care, and social connectedness. In addition, there are yes/no questions on 20 types of service utilization during the treatment episode. Dennis noted that the yes/no questions on service use are not able to capture change or important distinctions, such as that between 1 day or 10 days in a hospital.

Like the GPRA measure on substance use, the mental illness measure also lacks self-reported information about services received during key periods.

Dennis noted that neither of the GPRA data collection instruments includes measures of substance use disorder, although, as noted, some data on substance use are collected. The data collections do not include a scale or calculation of multi-morbidity, and they do not include quality–of-life measures. He added that the GPRA measures have no published psychometric properties, no maps onto existing literature, and no linkages to other measures or to NSDUH norms.

Dennis next described in further details the data collection approaches he had initially listed and provided some examples from his own work. In one study, he and his colleagues looked at how the duration of abstinence predicts the risk of relapse in the next year.[68] Using an event history approach, at the point of a 7-year interview the researchers asked how long from that 7-year point had participants been abstinent. The researchers found that if at year 7 a person had been abstinent for 1-12 months, by year 8 64 percent will have relapsed. If at year 7 a person had been abstinent for 1-3 years, only 35 percent will have relapsed by year 8. And if a person had been abstinent for 4-7 years, only 14 percent will have relapsed at year 8. Dennis said that this phenomenon is measured with a single item, and the results delineate a process. Consistent with other research, Dennis and his colleagues found that the turning point seemed to be around 3 years of abstinence when one begins to see some stability.

However, Dennis noted that recovery is not just about abstinence. To examine how the duration of abstinence is related to other aspects of recovery, the researchers looked at changes across three periods of abstinence in the same study. In the first 12 month of abstinence they found: more clean and sober friends; less illegal activity and incarceration; less homelessness, violence, and victimization; and less use by others at home, work, and among social peers. Between 1-3 years of abstinence, the researchers found: virtual elimination of illegal activity and illegal income; better housing and living situations; and increasing employment and income. The years 4-7 of abstinence were characterized by: more social and spiritual support; better mental health; continued improvement in housing and living situations; dramatic rise in employment and income; and dramatic drop in people living below the poverty line.

Dennis argued that instead of trying to define recovery by one number, which has been ruled out as a reasonable option by other speakers, simply adding a duration item to a data collection instrument makes it possible to convey the richness of how recovery changes over time. He added that this approach can also be useful to illustrate the duration of remission from substance use disorder, where most of the change happens in the first 1-3 years after remission.

As others have discussed, Dennis said, asking about multiple intervals or recency can involve questions about lifetime addiction, followed by questions about the past year, or just questions about the past year. In a yet unpublished study, he used data from the National Comorbidity Study and calculated the prevalence of remission for those with a disorder in their lifetime. Dennis noted that it makes a difference how the data categories are collapsed. Remission rates from drug use and remission rates from alcohol use are higher than remission rates from substance use overall, due to comorbidity. This is also true for remission from certain mental disorders, such as an overall category of anxiety in comparison with specific types of anxiety.

[68]Dennis, M.L., Foss, M.A., and Scott, C.K. (2007). An eight-year perspective on the relationship between the duration of abstinence and other aspects of recovery. *Evaluation Review*, 31(6), 585-612.

Dennis added that the higher the number of disorders included when studying remission, the fewer the number of people will be categorized as being in remission. Not factoring in this factor, especially when using community data, can lead to the incorrect impression that most people are getting better or getting better without treatment. The odds of getting better for people with three or four disorders is lower than for those with one disorder, and treatment and service is more important for them.

Dennis said that event history measures can be frequency, quantity of use, or problems by a specific calendar date. The method can capture start and end dates for episodes of abstinence, treatment, incarceration or other things in a log format. The data can then be used to approximate repeated measures by summarizing across multiple combinations of time periods (e.g., rates per week or year). One limitation of event history measures is that they are typically time consuming to collect, and the more dimensions are measured, the higher the burden on respondents. In addition, it can be difficult to have the right temporal order and get the timing of predictors right, unless this information is also collected with the same event history grid. Dennis said that this can be done to answer a specific question, but the burden can be very high.

Dennis argued that repeated measures are the *sine qua non* if one wants to study change over time. The follow-up could be limited to people with certain disorders and perhaps a random sample of people that do not have disorders. Studying change at the cohort level without repeated measures can lead to an ecological fallacy. For example, it may appear that at the group level there is steady improvement, particularly around the time of a treatment, but what is being observed is the mean value for the group. At the individual level, one study found that more than one-half of the people are changing status every year between relapse, incarceration, treatment, and recovery.[69] Dennis added that once the focus is on individual patterns, it is possible to assign probabilities to certain changes. For example, the probability of going from using in the community to being in recovery decreases as the number of mental health problems increases. The probability of sustaining abstinence increases as the number of sober friends increases. Dennis said that it is difficult to understand the process and see the influence of the various factors that have an impact on recovery unless repeated measures are used.

Dennis reiterated that multi-morbidity is an important consideration when studying recovery. Looking at the prevalence of several common past-year problems in the 2011 NSDUH, Dennis noted that 60 percent of the U.S. population has one or more of the following problems: any health problem, missed any work, any mental health problem, any substance use disorder, any school problem, any justice system involvement, or any violence. Of the sample, 20 percent had two or more of these problems in the past year. By contrast, most clients in treatment are showing up with three or more problems of this type. In other words, Dennis said, the two populations are not similar, and generalizations from one population to the other might not work. In addition, substance use disorder severity is strongly related to multi-morbidity. Co-occuring disorders are approximately 26 percent more likely in the case of severe substance use disorder. Finally, multi-morbidity is also related to health care utilization costs. Dennis added that the National Institutes of Health's common data workgroup[70] recommended a common set of 15 measures of service utilization (from the Global Appraisal of Individual Needs) and quality of life (from the EQ-5D instrument) that already have extensive norms.

[69]Scott, C.K., Foss, M.A., and Dennis, M.L. (2005). Pathways in the relapse-treatment-recovery cycle over 3 years. *Journal of Substance Abuse Treatment*, 28(2), S63-S72.

[70]See: www.phenx.org [June 2016].

Dennis concluded his presentation with a summary of his main points and some suggestions for SAMHSA. He said that recovery is a process and that it is important to understand how long it lasts and how facets change over time. Measuring lifetime remission is feasible, but requires at least two periods, with recency or repeated measures. Because people cycle through multiple periods of using, incarceration, treatment, and recovery, it is important to examine within person change and the predictors of transition. Multiple morbidity is important to measure and understand because it is common and affects the rates remission, service utilization, and cost. Finally, there is a need for more integration, norms, and cross validation of the NSDUH and GPRA measures, in the interest of better support for program evaluation.

Dennis argued that the number of items needed to measure recovery is a concern, especially if NSDUH is being considered as a potential data collection vehicle. One way to address this concern is to administer the questions to only a subset of the sample, oversampling those who have disorders and are likely to require services. Instead of screening for one disorder at a time, SAMHSA could consider screening for classes of disorders. Dennis pointed out that the 20-item Global Appraisal of Individual Needs Short Screener can identify 90 percent of the people that have a disorder and rule out 90 percent of the ones that do not. As discussed, a longitudinal component would be useful.

In terms of specific measures, Dennis said that he would add a one-item symptom duration question, as well as questions on the recency of symptoms for substance use disorder and internalizing and externalizing disorders. He said that this could be accomplished with approximately 20 questions, and more questions could be asked if the disorder is severe. Dennis said that a quality-of-life measure is also needed, whether the WHOQOL-8 or the EQ-5D, or something else. Finally, he said he also considers it important to add questions on service utilization.

Wilson Compton (National Institute on Drug Abuse) asked why SAMHSA has piloted only the WHOQOL-8 and not the EQ-5D? Essex said that the decision to test the WHOQOL BREF was made before she started working on the project, based on input from an expert panel. Once she came on board. the staff learned about the shorter version of the scale, the WHOQOL-8, and proceeded to pilot test that. Dennis added that the WHOQOL has some overlap with the SAMHSA definition of recovery, while the EQ-5D is just a measure of health-related quality of life, and it is very much focused on the absence of dysfunction.

Compton noted that it appears that adding quality-adjusted life years (QALYs) would be important. Dennis said that if one had the U.S. norms and could collect the data, then it could be done. Sherry Glied (New York University) said that the advantage of the EQ-5D is that everyone is using it for creating QALY measures, and so it is possible to use it across disorders, which would be ideal for policy purposes. Dennis commented that it is important to remember that replacing the WHOQOL-8 with the EQ-5D would mean that dimensions such as life satisfaction are not measured and would have to be introduced some other way.

8

Key Themes and Possible Next Steps

This chapter summarizes the discussions that took place at the end of the day, with the intent of synthesizing key themes and identifying the most promising approaches that meet SAMHSA's data collection goals of measuring recovery from substance use and mental disorders. Wilson Compton (National Institutes of Health) began by saying that at the beginning of the day he saw recovery as having, at the minimum, two components: one related to self-identity and the other related to behaviors or other external characteristics. The workshop discussions expanded his view and highlighted the need for multidimensional measures and measures that can capture the process of recovery.

Compton said that he is struck by the fact that measuring recovery seems more applicable to a treatment context than to a cross-sectional population survey context. In particular, he commented that he is not sure how measuring recovery could fit in the framework of the National Survey on Drug Use and Health (NSDUH). A survey such as the NSDUH seems to be the only type of vehicle that is suitable for producing national estimates, but it is not clear how data of defensible quality could be produced without imposing a major burden on respondents. Perhaps asking a small number of questions and providing a disclaimer that this is the best that one can do in a cross-sectional population survey is the only option.

In addition, if there is interest in measuring the process of recovery, Compton argued, there would be tremendous advantages associated with a longitudinal design. He added that some longitudinal studies exist and some were discussed throughout the day, but those are not large-scale, national surveys that would be suitable to address SAMHSA’s current goals.

Compton said that perhaps the most realistic approach may be simple measures, such as whether the person once had a problem but no longer does or just asking people whether they consider themselves to be in recovery, and, if applicable, how long the person has been abstinent. The discussion of the quality-of-life measures was interesting, he noted, and measures of that type could also be asked in a cross-sectional population survey. Compton said that he was intrigued by the positive mental health concept proposed by Corey Keyes (see Chapter 5) and will want to learn more about the measures and whether they are ready to be used in a large-scale population survey. He noted that it is clear that the concept of flourishing is somewhat distinct from the symptom and problem-based approach and could enrich the data.

Overall, Compton said that he was concerned that a prevalence estimate of recovery could be highly dependent on how the questions are asked: consequently, perhaps the best strategy would be to ask it in a number of different ways and then analyze the data. Some of the questions that have been used in the past to generate prevalence estimates could be included to provide additional context.

Compton said that one of the outstanding questions is whether recovery needs to be measured annually. He argued that the methods discussed seem to imply that collecting data on this topic every few years would be sufficient. It is also not likely that the prevalence of recovery would change substantially from year to year. If so, Compton said, it might be possible to

combine measuring recovery with a design that has several alternating modules on topics that do not change rapidly.

Sherry Glied (New York University) noted that she started off with the same general idea as Compton that there are two main aspects of recovery: the identity aspect and the symptomatology or remission aspect. The workshop discussions made her think that there are several key categories of concepts that are relevant. One of the relevant categories is the service provider role, and whether service providers have characteristics that facilitate recovery. This is an important question and therefore important to measure in some way. She argued that provider-oriented measures could be aligned with patient-centered care measures developed for other conditions.

In terms of the person-oriented measures, Glied said that it is obvious that identity is important, and one might want to just ask people whether they identify as being in recovery. Another concept that seemed to surface as key is remission. Remission and recovery are not the same thing, although there are overlaps in the two concepts. It appears, Glied noted, that work is needed to improve methods for asking about remission.

Another category of concepts includes such elements as housing, work, education, quality of life, impairments associated with the condition, and the extent to which a person is able to surmount those impairments. From a policy perspective, she argued, learning that there are many people who report that they are in recovery but have a terrible housing situation would be very useful information.

A final category of concepts relevant to recovery based on Glied's grouping consists of items such as self-efficacy, flourishing, and engagement. She argued that these are the types of questions that would be useful to ask of everyone, not only of people in recovery from substance use or mental disorder. A case could even be made for wanting to collect these data in a way that is not explicitly in the context of recovery.

Glied commented that it is clear that a large volume of research is being carried out on recovery in small, focused studies. The question, she said, is what are the advantages of a national population survey on this topic. One advantage is that a representative survey can produce a prevalence estimate, which can be used in a variety of different ways, including for advocacy purposes. Furthermore, the data can be used to conduct subgroup analyses, such as by cohort, race, ethnicity, income, and education, which may not be possible with smaller, more targeted studies. Finally, using national data may make it possible to have consistent comparisons across conditions, even across different mental health conditions, across different substance use conditions, or across mental health and substance use conditions, as well as conditions in other areas.

Glied argued that increased consistency in the measures used across national surveys would make them more robust. Consequently, it would be worthwhile to review the metrics that have been used in various national surveys and map them onto the concepts of interest to SAMHSA. It would also be useful to think about which surveys ask key relevant questions that could perhaps enable SAMHSA to add a one-time question about whether someone considers herself or himself to be in recovery and then continue to monitor changes in relevant areas without necessarily having to ask the question again.

As others have noted, Glied said, she also believes that it would be useful to do some longitudinal studies of highly targeted samples. However, a longitudinal study would be much more expensive than a cross-sectional design. She said that she does not like the idea of special studies, such as a follow-up study, because these types of efforts are often only funded once and

then disappear. If a question is added to an existing survey, it is likely to continue to remain on the survey.

Kim Mueser (Boston University) followed up on Glied's comment that some aspects associated with recovery, such as well-being and positive psychological health, could be useful to measure outside the context of recovery. He agreed with Glied that this would be useful, but he emphasized that some subjective aspects of recovery are really defined with respect to how one perceives a particular illness that they have experienced. For example, items such as empowerment, mental health recovery, and proactive coping, may really only be appropriate for people with an identified mental health condition because it has to do with their current position relative to that disorder. Glied asked whether, if that is the case, a national population survey is the right vehicle for detailed, specific questions. Mueser replied that targeted follow-ups of people in treatment may be a more appropriate context for those types of questions.

Mueser also noted that if the goal is to measure recovery in a general population survey, it is important to note that in the context of substance use, the concept of recovery resonates with a broader population than just those who are receiving treatment for substance use disorder. However, this is not necessarily the case in the context of mental illness, where the term recovery is not typically used outside of the treatment system.

Christine Grella (University of California, Los Angeles) noted that an argument for doing a nationally representative survey, in addition to the small-scale targeted studies that are more frequent in the field of recovery research, is that most smaller studies suffer from a selection bias. For example, study participants are typically recruited through recovery organizations or from clinical settings. She argued that collecting recovery data from a general population sample could mean tapping into populations that might surprise researchers. In addition, national data on a much broader range of people than before could inform policies and efforts to promote overall population health and counteract the negative images that are so prevalent about mental illness and substance use.

Hortensia Amaro (University of Southern California) said that national data could help lift the stigma associated with substance use and mental disorders and could raise support for funding dedicated to these areas. Corey Keyes (Emory University) commented that state-level data would be particularly useful—particularly the rates of those who have recovered and those who were in recovery and relapsed—in the context of the state prevalence rates of mental illness, serious mental illness, and substance abuse. The availability of this information could help with holding states accountable and also with showcasing states that are leaders in supporting recovery.

Alexandre Laudet (Center for the Study of Addictions and Recovery, National Development and Research Institutes, director emeritus) agreed with Compton that it is not necessary to collect data annually, but she argued that it would be useful to do it at least every 5 years. She said that it appears that there are two broad reasons for needing a prevalence estimate. First, SAMHSA provides block grants for the treatment of substance use and mental disorders, and the agency needs to know how many people may need recovery support services. Second, it is important to collect national data on people in recovery from substance use or mental illness because these populations and processes are poorly understood. For example, many of the current addiction-related laws stand in the way of people with substance use disorders getting their lives back together. It would be very useful to know if advocacy efforts and a potential decrease in stigma would prompt more people to pursue recovery. Successful

efforts to promote parity could be another development that could lead to more people accessing care, which in turn would be important to monitor.

Graham Kalton (Westat) proposed a modification to the suggestion that it may not be necessary to collect the data every year. He noted that it is possible that 1 year's data would not provide large enough sample sizes to be able to do subgroup analyses by different types of substance use or mental illness diagnoses. To avoid this potential problem, SAMHSA could plan on collecting data on recovery for 2 or 3 consecutive years to accumulate enough cases for such subgroup analyses and then pause for a few years.

Dean Kilpatrick (Medical University of South Carolina) reminded the group that SAMHSA's overall goal is to expand the collection of behavioral health data in several areas that include, in addition to recovery, specific mental illness diagnoses with functional impairment, serious emotional disturbance in children, and trauma. He wondered whether measuring these areas in isolation would be more difficult than designing a study that integrates all of these topics and measures them adequately. Based on the workshop discussions, he said, it seems that integrating a broad range of behavioral health measures into one survey could have major advantages and produce some very rich data. Such a new survey could perhaps be fielded every few years and maybe fielding the NSDUH could be paused for those years. Kilpatrick acknowledged that this suggestions may not be acceptable for NSDUH stakeholders.

Michael Dennis (Chestnut Health Systems) commented that taking a major national survey offline for several years would be extremely costly due to the expenses associated with shutdown and startup. The costs of the gaps could exceed the costs of fielding the survey every year. However, a feasible alternative might be to collect data from half of the sample in one year and another half of the sample in another year. If the data are only needed every 5 years, they could be collected from 20 percent of the sample each year, instead of collecting data from everyone every 5 years. Dennis also agreed with Glied's point that taking a survey offline could mean that it would stay offline, due to loss of funding in the interim.

Neil Russell (SAMHSA) said that he appreciated the input that collecting data every year may not be necessary and that the potential strategy of conducting one-off follow-up studies might be associated with a higher risk of a study being discontinued. He commented that it was good to learn that measuring recovery from substance use and mental disorder is a task that can be accomplished in some form. It is also useful to understand that most of the data that now exist on recovery are from specific populations and subgroups, and there are no nationally representative data from the general population that address the goals that SAMHSA has set forth for this effort. He also appreciated the perspectives on the importance of prevalence data on recovery from substance use and mental disorders.

Appendix A

Workshop Agenda

WORKSHOP ON INTEGRATING NEW MEASURES OF RECOVERY FROM SUBSTANCE USE OR MENTAL DISORDER INTO SAMHSA'S DATA COLLECTION PROGRAMS

The National Academies of Sciences, Engineering, and Medicine
Keck Center, Room 101
500 Fifth Street, NW
Washington DC 20001
February 24, 2016

PUBLIC SESSION

9:00-9:15 **WELCOME AND INTRODUCTIONS**

Hortensia Amaro, *Workshop Chair, School of Social Work, University of Southern California*

Connie Citro, *Director, Committee on National Statistics*

9:20-9:30 **SAMHSA'S GOALS AND CHALLANGES RELATED TO MEASURING RECOVERY FROM SUBSTANCE USE OR MENTAL DISORDER**

D.E.B. Potter, *Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services*

Neil Russell, *Director, Division of Surveillance and Data Collection, Center for Behavioral Health Statistics and Quality, SAMHSA*

9:30-10:10 **POLICY CONTEXT AND KEY CONCEPTS**

9:30-9:50 **Policy Context of Measuring Recovery from Substance Use**
Keith Humphreys, *School of Medicine, Stanford University*

9:50-10:10 **Policy Context of Measuring Recovery from Mental Disorder**
Kenneth Wells, *School of Medicine and School of Public Health, University of California, Los Angeles*

10:10-12:30 DEFINING AND OPERATIONALIZING RECOVERY

10:10-10:30 **SAMHSA's Definition of Recovery**
Donna Hillman and Steven Fry, *SAMHSA*

10:30-11:05 **Defining and Operationalizing Recovery from Substance Use**
Christine Grella, *Integrated Substance Abuse Programs, University of California, Los Angeles*

11:05-11:15 **What Does Recovery Mean to Those Who Self Identify as "in Recovery" from Substance Use?**
Alexandre Laudet, *Center for the Study of Addictions and Recovery, National Development and Research Institutes (Director Emeritus)*

11:15-11:25 ***Coffee Break***

11:25-12:00 **Defining and Operationalizing Recovery from Mental Disorder**
Kim Mueser, *Center for Psychiatric Rehabilitation, Boston University*

12:00-12:30 **The Role of Positive Mental Health in Operationalizing Recovery**
Corey Keyes, *Department of Sociology, Emory University*

12:30-12:45 FLOOR DISCUSSION

12:45-1:45 Lunch to Continue Morning Discussions
Third Floor Atrium

1:45-3:00 MEASURES OF RECOVERY

1:45-2:15 **Measures of Recovery from Substance Use**
Alexandre Laudet, *Center for the Study of Addictions and Recovery, National Development and Research Institutes (Director Emeritus)*

2:15-2:40 **Measures of Recovery from Mental Disorder**
Mark Salzer, *Department of Rehabilitation Sciences, Temple University*

2:40-3:00 **Discussion of Measures**

3:00-4:00	**DATA COLLECTION DESIGNS**
3:00-3:20	**SAMHSA's Recovery Measurement Pilot Study** Alyson Essex and Laura Jacobus-Kantor, *SAMHSA*
3:20-3:30	***Coffee Break***
3:30-4:10	**Tradeoffs of Different Data Collection Designs** Michael Dennis, *Chestnut Health Systems*
4:10-5:10	**PANEL DISCUSSION** Hortensia Amaro, *Workshop Chair, School of Social Work, University of Southern California* Wilson Compton, *National Institute on Drug Abuse, National Institutes of Health* Sherry Glied, *Graduate School of Public Service, New York University* James Jackson, *University of Michigan*
5:10-5:30	**FLOOR DISCUSSION AND WRAP-UP** Hortensia Amaro, *Workshop Chair, School of Social Work, University of Southern California*
5:30	**ADJOURN PUBLIC SESSION**

Appendix B

Biographical Sketches of Steering Committee Members and Speakers

HORTENSIA D. AMARO ***(Chair, Steering Committee)*** is associate vice provost for community research initiatives and dean's professor of social work and preventive medicine at the University of Southern California. Previously, she served as associate dean and distinguished professor of health sciences and of counseling psychology in the Bouve College of Health Sciences and as director of the Institute on Urban Health Research at Northeastern University. Her research interests include alcohol and drug use and addiction among adolescents and adults, substance abuse and mental health treatment for Latinos and African Americans, and alcohol and drug use among college populations. She is a member of the National Academy of Medicine. She has received numerous awards from professional, government, and community organizations and honorary degrees from Simmons College and the Massachusetts School of Professional Psychology. She founded five substance abuse treatment programs for women in Boston and served for many years on the board of the Boston Public Health Commission. She received a Ph.D. in psychology from the University of California, Los Angeles.

WILSON COMPTON ***(Member, Steering Committee)*** is deputy director of the National Institute on Drug Abuse (NIDA) of the National Institutes of Health. In this role, he provides scientific leadership in the development, implementation, and management of NIDA's research portfolio and conducts research to improve the prevention and treatment of drug abuse and addiction. Prior to his current appointment, he served as the director of NIDA's Division of Epidemiology, Services and Prevention Research. He led the development of a large-scale longitudinal population study to assess the impact of new tobacco regulations in the United States. Before joining NIDA, he was associate professor of psychiatry and director of the Master in Psychiatric Epidemiology Program at Washington University in St. Louis, as well as medical director of addiction services at the Barnes-Jewish Hospital in St. Louis. He has been the recipient of many awards from professional associations, including the Senior Scholar Health Services Research Award from the American Psychiatric Association, the Paul Hoch Award from the American Psychopathological Association, and the Health and Human Services Secretary's Award for Meritorious Service. He has an undergraduate degree from Amherst College and an M.D. from Washington University in St Louis.

MICHAEL L. DENNIS ***(Speaker)*** is senior research psychologist and the director of the Global Appraisal of Individual Needs (GAIN) Coordinating Center at Chestnut Health Systems in Bloomington, Illinois. He was the coordinating center principal investigator of the Cannabis Youth Treatment (CYT) study and the principal or co-principal investigator of more than a dozen other adolescent treatment experiments and grant programs. He is the primary developer of the GAIN—a standardized biopsychosocial assessment to help make clinical decisions about diagnosis, placement, and treatment planning--that is designed as a key piece of infrastructure to bridge the gap between clinical research and influencing practice to move towards evidenced based practice. He is currently chair of the Society for Adolescent Substance Abuse Treatment

and is a past chair of the Joint Meeting on Adolescent Treatment Effectiveness. He has a Ph.D. in psychology from Northwestern University.

STEVEN FRY ***(Speaker)*** serves as a Consumer Affairs Specialist at the Center for Mental Health Services at SAMHSA. He was a member of the Executive Leadership Team at the Connecticut Department of Mental Health and Addiction Services for six years prior to joining SAMHSA where he oversaw education and training, consumer rights and grievances, peer services and policies contributing to a recovery oriented service system. He has experience in behavioral health spanning inpatient, outpatient, community support and advocacy work since 1989. His own lived experience of recovery has informed his work bringing innovative and practical solutions in the areas of employment, peer services, and person centered planning to help individuals achieve economic and social inclusion. He has an M.S. in Community Mental Health from Trinity College of Vermont.

SHERRY GLIED ***(Member, Steering Committee)*** is dean of New York University's Robert F. Wagner Graduate School of Public Service. Her principal areas of research are in health policy reform and mental health care policy. She is a member of the National Academy of Medicine and the National Academy of Social Insurance. She previously served as professor and chair of health policy and management at Columbia University's Mailman School of Public Health. She also previously served as assistant secretary for planning and evaluation at the U.S. Department of Health and Human Services and as senior economist for health care and labor market policy on the Council of Economic Advisers under both President H.W. Bush and President Bill Clinton. She also participated in the Clinton Health Care Task Force. and she he has written several books on these topics. She has an M.A. in economics from the University of Toronto, and a Ph.D. in economics from Harvard University.

CHRISTINE E. GRELLA ***(Member, Steering Committee and Speaker)*** is professor-in-residence in the Semel Institute of Neuroscience and Human Behavior in the David Geffen School of Medicine at the University of California, Los Angeles (UCLA), where she is affiliated with the UCLA Integrated Substance Abuse Programs (ISAP)/Drug Abuse Research Center. Her research focuses on the intersection of multiple service delivery systems, including substance abuse treatment, mental health, child welfare, health services, HIV services, and criminal justice, focusing on the relationship of service delivery to treatment outcomes in these topic areas. She is currently a principal investigator on several studies, including a long-term follow-up study of gender differences among opiate users; the evaluation of a "trauma-informed" treatment program for women in prison; a study of the relationship between drug treatment and child welfare outcomes; and evaluations of several enhanced treatment interventions for various groups, including adolescents, homeless individuals with co-occurring disorders, and pregnant and parenting women. She has a B.A. in psychology from the University of California, Los Angeles, and an M.A. and a Ph.D. in psychology from the University of California, Santa Cruz.

DONNA J. HILLMAN ***(Speaker)*** is a Lead Public Health Advisor with the Performance Partnership Grant Branch of Center for Substance Abuse Treatment at the Substance Abuse and Mental Health Services Administration. She is the former state director for the Kentucky Division of Behavioral Health and has experience as a Licensed Professional Clinical Counselor with expertise in both mental health and substance use disorders. She was appointed by the

Governor of Kentucky to the Agency for Substance Abuse Policy, a group of agency leaders from all aspects of state government as well as community coalition leaders, provider representatives, and community leadership brought together to work on coordination of services and supports for persons with mental health and substance use disorders. Donna is also a person in long-term recovery. She has an M.S. in Education and Community Counseling from the University of Akron, Ohio.

KEITH HUMPHREYS ***(Speaker)*** is professor and section director for mental health policy in the Department of Psychiatry and Behavioral Sciences at Stanford University. He is also a senior research career scientist at the Health Services Research Center of the U.S. Department of Veterans Affairs (VA) and an honorary professor of psychiatry at the Institute of Psychiatry at King's College, London. His research addresses the prevention and treatment of addictive disorders, the formation of public policy, and the extent to which subjects in medical research differ from patients seen in everyday clinical practice. For his work in the multinational humanitarian effort to rebuild the psychiatric care system of Iraq and in the national redesign of the VA health system's mental health services for Iraq war veterans, he won the American Psychological Association's Award for Distinguished Contribution to the Public Interest. He has served as a member of the White House Commission on Drug Free Communities, the VA National Mental Health Task Force, and the National Advisory Council of the U.S. Substance Abuse and Mental Health Services Administration. During the Obama Administration, he spent a sabbatical year as Senior Policy Advisor at the White House Office of National Drug Control Policy. He has a Ph.D. from the University of Illinois, Urbana.

JAMES JACKSON ***(Member, Steering Committee)*** is the Daniel Katz distinguished university professor of psychology and professor of Afroamerican and African Studies at the University of Michigan. Previously, his positions at the University of Michigan included director of the Institute for Social Research and director of the African-American Mental Health Research Institute. He was the principal investigator of the National Survey of American Life, the largest survey about the physical, emotional, mental, structural, and economic conditions of Black Americans ever conducted. He is a member of the National Academy of Medicine and was recently appointed to the National Science Board. He has also served on the National Advisory Mental Health Council of the National Institute of Mental Health, the Advisory Council and Board of Scientific Counselors of the National Institute on Aging, and the Advisory Council to the Director for the National Institutes of Health. He is the recipient of the Robert W. Kleemeier Award for Outstanding Contributions to Research in Aging from the Gerontological Society of America; the James McKeen Cattell Fellow Award for Distinguished Career Contributions in Applied Psychology from the Association for Psychological Sciences; the Presidential Citation from the American Psychological Association; the Solomon Carter Fuller Award the American Psychiatric Association; Senior Health Policy Investigator from the Robert Wood Johnson Foundation; and the Medal for Distinguished Contributions in Biomedical Sciences, New York Academy of Medicine. He has a Ph.D. in social psychology from Wayne State University.

COREY LEE M. KEYES ***(Speaker)*** is the Winship distinguished research professor in the Department of Sociology of the College of Arts and Sciences at Emory University. His research centers on illuminating the "two continua" model of health and illness, showing how the absence of mental illness does not translate into the presence of mental health, and revealing that the

causes of true health are often distinct processes from those now understood as the risks for mental illness. The goal of his work is to better understand resilience, prevention of mental illness, and the health care approach called "predictive health," to maintain health and limit disease and illness. He has worked on health care transformation and public mental health with governmental agencies in Canada, Northern Ireland, Australia, and, in the United States, with the U.S. Centers for Disease Control and Prevention and the Substance Abuse and Mental Health Services Administration. He has an M.S. and a Ph.D. in sociology at the University of Wisconsin, Madison.

ALEXANDRE LAUDET ***(Speaker)*** is director emeritus and researcher at the Center for the Study of Addictions and Recovery at the National Development and Research Institutes in New York City. Her research has focused on elucidating what helps people with alcohol or drug problems quit drinking or getting high and how they stay in recovery. As a social psychologist, her main goals are to build the science of recovery and to help translate findings into services and policy that create opportunities for long-term recovery and improved quality of life for people with substance problems. She provides training and consultancy to government and community-based agencies on promoting opportunities for sustained recovery. She has a Ph.D. from the New School in New York City.

KIM T. MUESER ***(Speaker)*** is a clinical psychologist and executive director of the Center for Psychiatric Rehabilitation at Boston University. His clinical and research interests include family psychoeducation, the treatment of co-occurring psychiatric and substance use disorders, psychiatric rehabilitation for serious mental illnesses, and the treatment of posttraumatic stress disorder. He lectures and conducts workshops on psychiatric rehabilitation, both nationally and internationally. He received numerous awards, including the Armin Leob Research Award from the United States Psychiatric Rehabilitation Association; the Emily Mumford Medal for Distinguished Contributions to Social Science in Medicine, Department of Psychiatry, College of Physicians and Surgeons of Columbia University; and the Trail Blazer Award, Schizophrenia and Severe Mental Illness Special Interest Group of the Association for Behavioral and Cognitive Therapies. He has an M.A. and a Ph.D. in psychology from the University of Illinois at Chicago.

D.E.B. POTTER ***(Speaker)*** is program analyst with the U.S. Department of Health and Human Services Office of the Assistant Secretary for Planning and Evaluation (ASPE). Previously, she was a senior survey statistician at the Agency for Healthcare Research and Quality (AHRQ). She leads an ASPE, AHRQ and Centers for Medicare & Medicaid Services joint project to develop risk adjustment methods for quality measures for home and community-based services populations. Other responsibilities include managing the development of behavioral health quality measures and advancing quality measurement for the population with dementia. She serves on numerous technical expert panels and cross-agency workgroups. She has an M.S. in biostatistics from Georgetown University.

NEIL RUSSELL ***(Speaker)*** is director of the Division of Surveillance and Data Collection in the Center for Behavioral Health Statistics and Quality at the Substance Abuse and Mental Health Services Administration. His areas of expertise include behavioral health statistics and epidemiology; basic and applied research in behavioral health data systems and statistical

methodology; as well as surveillance and data collection. He has a Ph.D. in sociology from Arizona State University with a focus in survey research.

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COMMITTEE ON NATIONAL STATISTICS

The Committee on National Statistics was established in 1972 at the National Academies of Sciences, Engineering, and Medicine to improve the statistical methods and information on which public policy decisions are based. The committee carries out studies, workshops, and other activities to foster better measures and fuller understanding of the economy, the environment, public health, crime, education, immigration, poverty, welfare, and other public policy issues. It also evaluates ongoing statistical programs and tracks the statistical policy and coordinating activities of the federal government, serving a unique role at the intersection of statistics and public policy. The committee's work is supported by a consortium of federal agencies through a National Science Foundation grant.