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DISCLAIMER

The views, opinions, and content of this publication are those of the author and do not necessarily reflect the views, opinions, or policies of the Substance Abuse and Mental Health Services Administration/Center for Substance Abuse Treatment (SAMHSA/CSAT).

PROJECT GOALS

The goals of this project were to identify and describe the development, psychometric properties and uses of measures of recovery in the addiction field and to supplement this information by reviewing selected measures of recovery from other chronic conditions, including mental health disorders. This report provides a brief background summarizing the status of the concept of recovery in the addictions field and describes the approach used to identify and to select recovery measures. A summary of findings and recommendations are offered as closing statements.

BACKGROUND

Recovery as a Guiding Vision for Substance Abuse Services

Recovery, a concept once associated almost exclusively with 12-step fellowships such as Alcoholics Anonymous, is rapidly growing within the addictions field. Among Federal agencies, this includes the National Institute on Alcohol Abuse and Alcoholism (NIAAA) renaming its Division of Treatment to Division of Treatment and *Recovery* Research, the White House's 2003 *Access to Recovery* (ATR) program, the Center for Substance Abuse Treatment's *Partners for Recovery* (PFR) initiative, *Recovery Community Services Program*, and *Recovery Month* campaign and State Offices of Alcoholism and Substance Abuse Services' inclusion of recovery services on their websites (e.g., New York State). There is also a growing grassroots movement of organizations such as Faces and Voices of Recovery.

Under SAMHSA's leadership, (Center for Substance Abuse Treatment, 2006) significant paradigmatic shifts are under way in substance abuse services. Growing evidence for long addiction and treatment 'careers' consisting of multiple cycles of intensive and costly treatment episodes (Dennis, Scott, Funk, & Foss, 2005) followed by return to active addiction (Scott, Foss, & Dennis, 2005) has led to the conclusion that the prevalent acute-care model is ill suited to address substance use disorders (SUD) as a chronic condition (Hser, Anglin, Grella, Longshore, & Prendergast, 1997; McLellan, 2002; McLellan, McKay, Forman, Cacciola, & Kemp, 2005; O'Brien & McLellan, 1996). Noting the deficiencies of the current system and the many similarities between SUD and other chronic illnesses, the Institute of Medicine and leading addiction researchers have called for SUD treatment to shift from the acute care model to one of recovery management akin to the chronic care model used in the treatment of other chronic conditions (Dennis & Scott, 2007; Dennis et al., 2005; Humphreys, 2006; Institute of Medicine, 2005; McKay, 2005; McLellan, Lewis, O'Brien, & Kleber, 2000; Miller, 2007; Moos, 2003; White, Boyle, & Loveland, 2002; White, Boyle, Loveland, & Corrington, 2005).

While the most prevalent form of recovery management (RM) has historically been participation in 12-step fellowships (Humphreys et al., 2004) and methadone maintenance, this concept of recovery is changing. A growing menu of recovery-support services emphasizing post-treatment monitoring and support include telephone-based continuing care (McKay, Lynch, Shepard, & Pettinati, 2005), "recovery management checkup" (RMC) and early re-intervention (Scott &

Dennis, 2002), recovery homes (Jason, Olson, Ferrari, & Lo Sasso, 2006), recovery coaching, and assertive linkage to communities of recovery (Scott, White, & Dennis, 2007). Available evidence suggests that the recovery management approach is effective at minimizing relapses (Godley, Dennis, Godley, & Funk, 2004; McKay et al., 2005; Scott, Dennis, & Foss, 2005) and also cost effective (Zarkin, Dunlap, Hicks, & Mamo, 2005; French et al., 2000). The shift from acute to chronic care is increasingly occurring in the context of an even more fundamental change in SUD services, a shift driven by converging forces that include a transformation in the mental health field with its focus on consumer-driven recovery-oriented services, research findings supporting the need for comprehensive individualized services, changing norms and expectations of services as defined by Institute of Medicine's reports (Institute of Medicine, 2001 and 2005), key leadership at the national and State level such as in Connecticut and New York and in the city of Philadelphia (Clark, 2007; Evans, 2007; Kirk, 2007), and an emerging and energized recovery community (Kaplan, 2008).

Further, a framework is beginning to emerge, Recovery-oriented Systems of Care (ROSC), that provides person-centered, self-directed approaches to care that build on the strength and resilience of individuals, families and communities to take responsibility for their health, wellness, and recovery from alcohol and drug problems across the lifespan (Clark, 2008). ROSC (<http://www.pfr.samhsa.gov/rosc.html>) offer a multi-system, comprehensive menu of services and supports that can be coordinated and integrated to meet the individual's needs and chosen pathways to recovery (Connecticut Department of Mental Health and Addiction Services, 2006). These services may include education, employment and job training, housing services, childcare, transportation to/from treatment and work, case management and linkage to other services (e.g., legal, food stamps), outreach, relapse prevention, recovery support services, substance abuse education for family members, peer-to-peer services and coaching, self-help and support groups, life skills, faith and spiritual support (Kaplan, 2008). The system in ROSC is not a treatment agency but a macro-level organization of a community, region or State (e.g., Connecticut). Shifting from a deficit-based perspective to a recovery-oriented, asset-based perspective (Connecticut Department of Mental Health and Addiction Services, 2006) requires fundamental changes at the systems, program, and staff levels including changes in financing, front-line service practices (McLellan, Carise, & Kleber, 2003), and service relationships (McLellan et al., 2005). At this writing, more than a dozen States and municipalities have adopted ROSC - most notably CT, NJ and the city of Philadelphia (Evans, 2007; Kaplan, 2008), with many others at various stages of the transition. The momentum is growing steadily, as evidenced by a recent National Symposium where many Single State Agencies reported on their changing system (http://www.ireta.org/ireta_main/recovery-symposium.html) (Alcoholism & Drug Abuse Weekly, 2008) and by the theme of the June 2008 conference of the National Association of State Alcohol and Drug Abuse Directors (NASADAD): "Prevention and treatment services in support of recovery-oriented systems of care."

What is Recovery?

Although viewed as an overarching tenet for over half a century, 'recovery' has until recently, remained undefined, hindering both clinical practice and research (Belleau et al., 2007; Laudet,

2007; Maddux & Desmond, 1986). As ‘recovery’ is increasingly becoming a guiding vision in the substance abuse field, Federal agencies (Center for Substance Abuse Treatment, 2006), independent panels (Belleau et al., 2007) and researchers (Laudet, 2007) have begun to recognize the need to formulate a working definition of ‘recovery’.

Historically, there has been an implicit assumption that resolving the (usually) primary substance use problem (i.e., attaining abstinence) would by itself produce improved function in other domains—the so-called ‘addiction-related’ domains (e.g., physical and mental health, social function, living conditions). Indeed, abstinence from drugs and alcohol has been considered a proxy for good function in other areas that comprise recovery (McLellan, Chalk, & Bartlett, 2007). While most would agree that abstinence or, at the very least, significant reductions in substance use, is a prerequisite for sustained improvement in the other life domains, the connections between substance use and functional status in the other life areas are complex (McLellan, Luborsky, Woody, O'Brien, & Kron, 1981; Simpson, 1981). Like other chronic conditions, recovery from SUDs involves remission of the disease and its symptoms and the ability to attain quality of life. We cannot assume that a client who is abstinent is also employed, not committing crimes, and physically healthy (McLellan et al., 2007), as abstinence rarely brings instant relief (Vaillant, 1995). By the time severely dependent persons achieve abstinence, which often comes after two decades of active addiction (Dennis et al., 2005), physical and mental health may have deteriorated and chronic conditions may have progressed (e.g., HCV, HIV, disease of the liver, lungs); employability, family and social relations, finances and housing have often severely deteriorated as well (Yeh, Che, Lee, & Horng, 2008). All these domains require extended time to improve, even in the presence of abstinence. Though abstinence is generally associated with *some* improvement in other areas of functioning (Dennis, Foss, & Scott, 2007; Kraemer et al., 2002) it is not atypical to see improvement in drug use without significant *concurrent* improvement in other life areas (McLellan et al., 1981; Bacchus, Strang, & Watson, 2000; Dennis et al., 2007).

The emerging consensus is that recovery from SUD goes well beyond abstinence (McLellan et al., 2007). CSAT, therefore, views recovery as: *“A process of change through which an individual achieves abstinence and improved health, wellness, and quality of life”* (Center for Substance Abuse Treatment, 2006). Other recent definitions concur. The Betty Ford Institute expert panel stated that: “Recovery from SUD is a voluntarily maintained lifestyle characterized by sobriety, personal health, and citizenship” (Belleau et al., 2007). A recent study showed that persons in recovery experience recovery as *a process of change, growth, and improvement in all life areas affected by active addiction* - cognitive function, social relations, living conditions, mental and physical health (Laudet, 2005; Laudet, 2007). The Director of SAMHSA has said that *“Recovery is when patients are not just free of symptoms - they have a life”* (Curie, 2005). This is consistent with the experience of persons in recovery: “My definition of recovery is life. ‘Cause I didn't have no life before I got into recovery” (Laudet, 2007, p.249).

Need for Recovery Measure

Quality and accountability have become of paramount importance in all health care (Institute of Medicine, 2001), where the need for performance measures to monitor and improve quality and foster accountability in the delivery of services designed to initiate, sustain and promote recovery is

increasingly recognized (Center for Substance Abuse Treatment, 1995; Garnick et al., 2007; Garnick et al., 2002; McCarty, 2007; Pelletier & Hoffman, 2001; Soldz, Panas, & Rodriguez-Howard, 2002; Substance Abuse and Mental Health Services Administration, 2008; The Washington Circle, 2007). Among the central features of ROSC are that it is outcome-driven, research-based and requires ongoing monitoring and feedback for systems improvement (Center for Substance Abuse Treatment, 2006). (Clark, 2008) Guided by a broader conceptualization of recovery (as discussed above), SUD service systems need an assessment tool for internal quality monitoring and service improvement, and for external accountability. At the individual client level, ROSC-guided SUD services need a tool to track change and identify the need for specific services and supports as recovery services continue to grow. Recovery-oriented systems recognize the ebb and flow of progress within and across life domains and use progress in one domain to prime improvement in other domains (White et al., 2005). Moreover, a recovery measure is needed for researchers to elucidate recovery processes, patterns and their determinants, as well as to guide services and to begin identifying recovery ‘milestones’ that provide realistic expectations to service providers, persons in recovery, their families and to society at large.

PROJECT METHODS

Identification of Potential Instruments

This project was conducted under the Partners for Recovery (PFR) initiative during November-December 2008. Instruments presented in this report were identified through three primary strategies designed to maximize reach in terms of the sources and types of instruments identified. The three following strategies were used to identify instruments for possible inclusion in this report:

1. ***Scientific Literature Review:*** Electronic database of English-language scientific articles (primarily PubMed and PsycINFO) were searched on terms such as [(chronic condition) AND (recovery)].
2. ***General Web-based search:*** Worldwide web searches were conducted using the Google search engine on terms similar to those used for the scientific article search that yielded numerous reports, conference presentations and articles published, for instance, in newsletters; when a document yielded information about an instrument name or an ongoing recovery measure development project, that information was tracked via web with the ultimate goal of locating the instrument described or contacting an individual to ask about the instrument(s) used in a recovery-related project.
3. ***Outreach to stakeholder groups:*** Given the stated goal of this project to identify measures that are used in service settings, representatives were reached through established contacts developed with stakeholders in addictions recovery over a decade of work. This includes addiction researchers; experts in the development of performance measures (e.g., the Washington Circle Group, the Avisa group); peer-led recovery organizations (e.g., the Connecticut Community for Addiction recovery – CCAR); recovery advocacy organizations (e.g., Faces and Voices of Recovery); State and city

agencies, especially those that have implemented recovery-oriented services (Connecticut, Vermont, the city of Philadelphia) or are in the process of implementing recovery-oriented services (e.g., New York State Office of Alcohol and Substance Abuse Services [OASAS]); treatment agencies nationwide, both public and private (e.g., NYC and CA treatment programs, Hazelden, Samaritan village, Promises Malibu; Association of Recovery Schools), addiction professional organizations (Institute for Research, Education, and Training in Addictions [IRETA], the Addiction Technology Transfer Centers [ATTCs], the National Association for Addiction Treatment Professionals), organizations conducting or evaluating Federally-funded recovery-oriented programs such as Access to Recovery (ATR) and their project officers. Many of these contacts yielded additional potential avenues that were pursued/contacted as well.

Overall, responses from this large outreach effort fell into one of two categories, the overwhelming majority (~80%) reported knowing of/using no recovery measure, many adding comments such as “we could certainly use a recovery measure, please send me what you find!” The second category reported using or recommended ad-hoc measures most often developed in-house based on the growing database of research reports and other writing on ‘recovery’ freely available on the worldwide web, without the benefit of measurement development or psychometric training. The only notable exception, the State of Connecticut that was the first in the nation to implement a recovery orientation nearly a decade ago (Kirk, 2007) has since made great strides in identifying and using standardized instruments to assess the construct of ‘recovery:’ the Recovery Self-Assessment instruments as well as the World Health Organization’s Quality of Life (WHOQOL) measure, both included in this report.

Instrument Selection

Nearly thirty measures were identified and considered as a result of the above strategies. The initial intent of this project was to identify and review measures of recovery with a focus on the addiction field. The search targeted measures developed through standard multistage measure development techniques that typically combine initial qualitative work followed by comprehensive statistical analyses to determine the structure and psychometric properties of the candidate instrument, that were currently used in the service setting. Upon early review, it became evident that no such measure exists in the addiction field; the few instruments identified are either performance measures to assess services (e.g., the Client Assessment Inventory-CAI), or measures developed in other fields (e.g., WHOQOL). Recovery measures emanating from the mental health field were numerous and many are the product of comprehensive psychometric efforts though most of these instruments do not appear to be used systematically either in research or in the service setting. Rather, it seems that parallel measure development projects are ongoing from various stakeholder groups, most involving consumers of services and it is not clear at this writing whether a single or even a handful of these instruments will emerge as ‘the’ yardstick to measure mental health recovery outcomes. Note that this is not surprising since the definition of recovery varies according to who does the defining (service providers, policy makers and funders, consumers of services), in addition to the obvious fact that recovery is an

intensely personal and individual experience – though as discussed later, common dimensions emerge from all the instruments identified here.

In conducting this project and especially in identifying and selecting measures for possible inclusion, we were guided by a comprehensive effort conducted in the mental health field originally published in 2000 and most recently updated in 2005: the Evaluation Center’s mental health recovery measure compendia assembled by Ralph and colleagues and by Campbell-Orde and colleagues (Campbell-Orde, Chamberlin, Carpenter, & Leff, 2005a; Ralph, Kidder, Muskie, & Phillips, 2000). The 2005 volume details instrument review criteria and provides the form used to do so, a system used for this project wherever feasible. Based on this, on the instruments and related documents that were identified for this project, the following criteria guided our selection:

- Instrument assesses the experience of the person ‘in recovery’ (rather than a service provider) and does not focus exclusively on services (quality or outcome of services)
- Designed for self-administration
- Existing or ongoing evaluation of psychometric properties and overall structure (e.g., subdomains)
- Easily available, ideally in the public domain
- Brevity (ideally under 50 items, ~10 minutes)
- Evidence of measure’s ability to quantify change was strongly preferred. However, few of the measures identified have been evaluated on this criterion. Therefore we decided to record whether or not this aspect of the measure has been assessed rather than to make this an inclusion criterion.
- Similarly, evidence of ongoing use in the service setting (or in research) was strongly preferred but was relatively rare so again, available information on current measure use is noted under individual measure sections.

Categorization Criteria

Faced with the need to assess recovery outcomes and lacking a dedicated tool to do so, addiction professionals have adopted instruments developed in other fields to fill the gap. As described below, measures of mental health recovery (e.g., the Recovery Self-Assessment, RSA) and generic measures of wellness or quality of life (the World Health Organization Quality of Life Instruments, WHOQOL) are increasingly being used in the addiction field. As a result, several categorization schemes were considered for this report. In the end, we elected to preserve the three original categories and to note each measure’s use in the area where it applied. Therefore the measures are presented under the category that corresponds to the field of inquiry from which they emerged: addiction, mental health or other conditions.

Table 1. Summary Table of Instruments

Measures of Addiction Recovery

Instrument Name	Authors	Number of Domains	Domains	Number of items	Psychometrics *		
					Internal Consistency	Test Retest	Convergent Validity
Modular Survey	Doucette, 2008; Forum on Performance Measurement	4	Quality of services, perceived outcome improvement, connectedness, commitment to change	21	X	planned	planned
Recovery Capital Measure	Sterling et al, 2008	8	Reliance on God and faith; Spirituality; Recent sobriety; Stable income; Alcohol/drug-free environment; % lifetime spent free from the effects of substance use; Satisfaction with living situation; Amount of education/training	23	planned	planned	planned
Client Assessment Summary	Kressel et al, 2000	4 broad dimensions, 14 domains	Dimensions: Developmental, socialization, psychological. Community membership	14	X	N/E	N/E

Measures of Mental Health Recovery

Instrument Name	Authors	Number of Domains	Domains	Number of items	Psychometrics *		
					Internal Consistency	Test Retest	Convergent Validity
Illness Management & Recovery Scales (IMR)	Mueser et al 2004 & 2005	N/A	No domains: measures dimensions critical to illness management	15	X	X	X
Mental Health Recovery Measure	Young & Bullock, 2003	7	Overcoming 'stuckness,' Empowerment, Well-being, Advocacy, Basic functioning, Learning, New potentials + 2 Spirituality items	30	X	X	X
Recovery Assessment Scale (RAS)**	Giffort, et al., 1995	5	Personal Confidence and Hope, Willingness to Ask for Help, Goal and Success Orientation, Reliance on Others, and No Domination by Symptoms	41	X	X	X
Recovery Self-Assessment Instruments (RSA)**	O'Connell, et al 2005	5	Diversity of Treatment Options, Consumer Involvement and Recovery Education, Life Goals vs. Symptom Management, Rights and Respect, Individually-tailored Services	36	X	N/E	N/E

N/A =Not applicable

* N/E = psychometric property not examined

** Systems Level Measurements

Measures Developed for Other Chronic Conditions

Instrument Name	Authors	Number of Domains	Domains	Number of items	Psychometrics *	Psychometrics *	Psychometrics *
					Internal Consistency	Test Retest	Convergent Validity
Measure of Resources and Supports for Chronic Illness Self-Management	McCormack et al., 2008	5	Individualized assessment; collaborative goal setting; enhancing skills; ongoing follow-up and support; community resources	17	X	N/E	N/E
PROMIS	PROMIS Cooperative Group	3	Physical health, mental health, social health	N/A	ongoing; see website http://www.nihpromis.org	ongoing; see website http://www.nihpromis.org	ongoing; see website http://www.nihpromis.org
World Health Organization Quality of Life Instrument (WHOQOL -100)	WHOQOL Group	6	Physical, psychological, social, living environment, independence, spiritual	100	X	X	X
World Health Organization Quality of Life Instrument (WHOQOL - BREF)	WHOQOL Group	4	Physical, psychological, social, environment + 2 overall QOL items	26	X	X	X

N/A =Not applicable

* N/E = psychometric property not examined

** Systems Level Measurements

MEASURES OF ADDICTIONS RECOVERY

Modular Survey

Design: Addresses the need to measure quality

Authors: SAMHSA–supported initiative conducted under the auspices of the Forum on Performance Measurement and the Washington Circle

<http://www.washingtoncircle.org/consumer.html>

Source: Doucette, 2008

Person contacted: John Bartlett, PhD, the Avisa Group, who served as Executive Director of the Forum on Performance Measurement and Chair of the Modular Survey Steering Committee: jbartlett@avisagroup.com

Purpose: To identify and develop common indicators and measures of consumer perception of care, a National Outcomes Measure (NOMs) domain, across the SUD and mental health field. Specific criteria: Identify a small set (of psychometrically sound, public domain, non proprietary items from measures with existing datasets that assessed service system quality and client outcome in behavioral health care; applicable to adults and to youths.

Methods overview: Review existing instruments, generate additional items/domains, statistically derive final set of domains and instrument in pilot test.

Methods specifics: Two-phase approach

- PHASE 1: Consensus-driven, conducted in conjunction with mental health professionals to focus on commonality, not comprehensiveness.
 - Four workgroups (Adult content and Youth content, Methods and Steering Committee)
 - Three instruments selected for potential inclusion of items: The Mental Health Statistics Improvement Program Consumer Survey (MHSIP); the Experience of Care and Health Outcomes Survey (ECHO) and The Youth Services Survey (YSS).
 - Four domains selected: (a) access to services; (b) appropriateness of services; (c) satisfaction with services; and (d) perceived improvement as a result of services.
 - 17 selected items pilot-tested in collaboration with United Way in Cincinnati among ethnically-diverse samples of recipients of behavioral health care (N = 856 adults, 301 youths)
 - Examination of psychometric properties of the items
 - 11 items retained yielding a two-factor model: (a) quality/appropriateness of services; and (b) outcomes (perceived improvement as a result of services).
- PHASE 2: Substance abuse specific

-
- Substance use disorder item content workgroup representing all stakeholder groups
 - Review the items developed in Phase I
 - Identify additional domains (e.g., social connectedness, therapeutic/helping alliance, stage of change, problem recognition, trigger points associated with relapse and recovery)
 - Generate items using the Item mapping and writing workshop approach
 - Item content workgroups separate into two groups: adult and youth-related content
 - Q-sort method and content validity analysis yielded 52 items (including the 11 items from Phase I) including several judged redundant
 - All 52 items reviewed by the Forum Methods Committee
 - 35 items retained and pilot tested among ethnically-diverse samples of recipients of behavioral health care (two adult samples $N_1 = 1,087$ and $N_2 = 462$, youth sample $N = 492$). [Data from the second adult sample is to be used to determine the stability of the measurement model and the psychometric properties of the instrument.]
 - Iterative process of IRT theory (Rasch measurement), factor analyses and related statistical work on the adult sample I and the adolescent data followed by examination of items in relation to those retained in Phase I.
 - Four-factor structure retained: overall quality of services, perceived outcome improvement, connectedness (family, social, therapeutic alliance) and commitment to change.
 - Final scale consist of 21 items
 - Reliability (coefficient alpha) for the 4 domains in both adult sample I and adolescent sample examined and found adequate ($>.80$)
 - Selection of response scale: 4-point Likert type scale (Disagree, somewhat disagree, agree, strongly agree)
 - Differential item function/item bias analyses to examine potential bias on terms of gender or race/ethnicity in the adult sample as well as age in the adolescent sample

Next steps: Contingent on continued funding, the measure developers recommend:

1. Standardize the administration (including web-based) and scoring protocols
2. Move to actionable information (e.g., address NOMS and GPRA domains)
3. Further psychometric and field testing

Application for Recovery Measurement: The measure is brief and psychometrically strong; as such it is a good example of the development work needed to create a recovery measure. It focuses mostly on services and lacks some of the domains that are key to persons in recovery, most notably living environment, and employability.

Recovery Capital Measure

Authors/source: Sterling, Slusher, & Weinstein, 2008

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Background: The authors of the first volume of the Evaluation center's Compendium of Recovery and Recovery-Related Instruments (Ralph et al., 2000) argued that "The measurement of recovery must also delve into what influences or helps recovery take place" (p. 4). The concept of *recovery capital* introduced into the addiction field in 1999 (Granfield & Cloud, 1999) refers to the amount and quality of internal and external resources that one can bring to bear to initiate and sustain recovery from addiction. Though consisting strictly of social factors when originally introduced, the construct has been broadened to include individual factors (e.g., spirituality, life meaning/purpose) by other groups of researchers and proven a significant predictor of positive recovery outcomes - abstinence, quality of life satisfaction and stress (Laudet & White, 2008).

Purpose: To develop a psychometrically sound method for assessing the quality and quantity of recovery capital.

Conceptual framework: Strength-based, recovery-oriented approach consistent with the conceptualization of addiction as a chronic condition (McLellan et al., 2000) and with SAMHSA's emerging Recovery-Oriented Systems of Care (ROSC) framework (Clark, 2007; Clark, 2008).

Development. A battery of existing measures tapping relevant domains was administered to 405 individuals who sought voluntary admission for inpatient alcohol dependency treatment (39% women); the instruments were administered at intake and at end-of-treatment (approximately 4 weeks later). The instruments included in the test battery were: The Drug Taking Confidence Questionnaire (DTCQ), a 50-item measure of abstinence efficacy (Annis, Sklar, & Turner, 1997); the Addiction Severity Index (ASI - McLellan, Luborsky, Woody, & O'Brien, 1980); the Daily Spiritual Experiences-Long Form (DSE), a 16-item measure of the individual's perception of the transcendent that makes spirituality its central focus and can be used effectively across religious boundaries (Underwood & Teresi, 2002); the Fetzer Institute and National Institute on Aging Working Group's Brief Multidimensional Measure of Religiousness/Spirituality – BMMRS (Fetzer Institute and National Institute on Aging Working Group, 1999), a 32-item multidimensional measure of major domains of religious and spiritual experience; the Spiritual Belief Scale (SBS), an 8-item measure of spiritual thinking based on AA philosophy (Schaler, 1996) and the Spiritual

Experience Index (SEI), a 23-item scale of spiritual maturity (Genia, 1997). The ASI and the DTCQ were re-administered to 60% of participants three months post-treatment follow-up as a test of the predictive validity of the newly developed aggregate measure. Standard statistical tests were conducted to examine the factorial structure of the combined items.

Review of the study intake instruments yielded an initial pool of 77 potential recovery capital items. The 43 items tapping spirituality were subjected to exploratory factor analysis (EFA) in an attempt to balance the item mix. Ten spirituality oriented items loading were retained for scale construction that were added to the 34 other items and subjected to a second EFA. Consistent with the multidimensional nature of the recovery capital, the final instrument consists of 23 items representing 8 domains that explain 71.4% of the variance in the original correlation matrix.

Instrument domains/factors:

1. Reliance on God and faith as a means of coping
2. Overarching sense of spirituality
3. Recent sobriety
4. Stable employment/income
5. Alcohol/drug-free living environment
6. Proportion of one's life spent free from the debilitating effects of alcohol, operationalized as number of years sober/age
7. Satisfaction with marital situation and living arrangements
8. Amount of formal education/training

Psychometric properties:

Using a cumulative factor score (i.e., the sum of the eight factor scores converted to t-scores to eliminate negative values), the authors examined the predictive utility of this new measure, relationships with a variety of proximal (end-of-treatment craving estimates) and distal measures, including DTCQ and ASI composite scores at 3-month follow-up, as well as reports of the number of days of alcohol use and alcohol related problems at follow-up. Results were significant only for end-of-treatment craving and for drug abstinence self-efficacy.

Next steps: Prospective development and testing of the items are planned.

Application for Recovery Measurement: Recovery capital is a relatively new and promising concept in recovery research. The instrument covers a broad range of domains that are critical to recovery at successive stages of the process and is applicable to a variety of recovery 'paths' (treatment, self-help, natural recovery); it can therefore be useful in quantifying individuals' available resources and to identify services/support needs. The measure is in the early phase of development, more psychometric and field-testing work is needed.

The Client Assessment Inventory (CAI – long form), Client Assessment Summary (CAS), the Staff Assessment Summary (SAS)

Authors/Source: Kressel, De Leon, Pali, & Rubin, 2000

Person contacted: David Kressel, Ph.D., National Development and Research Institutes, Inc.

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Purpose: To develop instruments that measure client self-report and staff evaluation of client progress in the Therapeutic Community (TC) environment

Approach:

- Theoretically driven based on the framework of the TC approach that conceptualizes addiction as a disorder of the whole person and as a symptom, rather the essence of the disorder (De Leon, 1995; De Leon, 1996; De Leon, 1997; De Leon, 2000).
- Started from an earlier instrument, the Therapeutic Community Client Progress Scales (TCCPS) consisting of seven scales (Jainchill, 1992), the authors sought to extend the conceptual reach of the measure to assess *multidimensional change* that reflects the TC's complex perspective of the individual and the recovery process.

Development:

- Focus groups established a correspondence between the theoretical formulation and the way staff and residents of a TC see the change process:
 - Agency executive staff evaluated potential benefits of utilizing the instruments and to develop procedures for implementing the study.
 - Clinical staff clarified and interpreted the domains of client progress in treatment in each of the four dimensions including establishing critical components of the domains and describing what these domains look like in practice.
 - TC residents translated the items in each domain into statements with wording relevant to the clients' experiences in treatment.
- Field test: Sample of 346 residents at two location of a TC (Daytop Village) stratified by time in treatment: 78 clients (22.5%) at 1–3 months, 95 clients (27.5%) at 4–6 months, 73

clients (21.1%) at 7–9 months, and 100 clients (28.9%) at 10 or more months to allow cross-sectional examination of client measure’s ability to assess change.

Instruments: Three forms of the progress instrument were constructed. All three forms items are rated on a 5-point Likert scale ranging from “strongly disagree” to “strongly agree”.

1. **The Client Assessment Inventory** (CAI – long form) is a self-report form that contains 98 items along the 14 scales, one scale for each domain. The CAI total score reliability coefficient is 0.97. The individual scale reliabilities range from 0.65–0.86. The CAS score has a reliability coefficient of .87 the SAS score is 59% of the maximum possible and has a reliability coefficient of 0.95. Confirmatory factor analysis showed that each of the 14 scales is consistent with the hypothesis of a single underlying factor for each scale.
2. **The Client Assessment Summary** (CAS) is a brief client self-report form that contains 14 new items, each summarizing one of the 14 theoretical domains. Three factors underlying the responses to these items: a developmental factor, a psychological factor, and a combined community member and socialization factor. The CAS score is 75% of the maximum possible score and has a reliability coefficient of .87. Preliminary cross-sectional evidence of the CAI and CAS’s capacity to measure change is obtained from examining domain scores across the four previously defined cross-sectional time-in treatment categories.
3. **The Staff Assessment Summary** (SAS), a short form completed by staff to evaluate their clients’ progress in treatment, consists of the same 14 domain summary items in the CAS. The staff and client short instrument (CAS) individual item and scale summary ratings can be directly compared because the client and staff summary scales contain the same items. The SAS score is 59% of the maximum possible and has a reliability coefficient of 0.95. The items were reduced to four scales that represent the higher order dimensions of developmental, psychological, socialization, and community membership. Cronbach alphas for these four scales ranged from 0.82–0.93 and there were intercorrelations among these four scales that ranged from 0.77–0.83, which suggests that there may be a single factor that underlies these four dimensions.

Dimensions and domains:

- Four broad dimensions: Developmental, socialization, psychological (cognitive/emotional), and Community Member Dimension (the evolution of the individual’s relationship to the therapeutic community, with particular reference to the quantity and quality of program engagement and participation).
- Fourteen domains: Maturity (self-regulation, social management), Responsibility (accountability, meeting obligations), Values (integrity, right living), Drug/Criminal Lifestyle (social deviancy), Maintains Images (social vs. antisocial lifestyle), Work Attitude (attitude appropriate for the work world), Social Skills (ability to relate to people), Cognitive Skills

(awareness, judgment, insight, reality testing, decision-making, and problem-solving skills), Emotional Skills (communication and management of feeling states), Self-Esteem/Self-Efficacy (sense of well-being), Understands program rules, philosophy, and structure, Community engagement and participation, Attachment, investment and stake in the community, and Role Model (lives by example, teaching others)

Psychometric Properties of the Progress Instruments:

- Data collection with the three instruments was conducted for one year at two adult residential TC facilities. Findings show that the instruments reliably measure client progress in treatment. Analysis of data on 346 clients revealed CAI, CAS and SAS Cronbach Alphas of 0.97, 0.87 and 0.95, respectively.
- The Pearson correlation coefficients of the CAI with the CAS exceed 0.9. Initial CAS scores are consistently higher than initial SAS scores, however client and staff progress scores become more concordant the longer the client remains in treatment. That is consistent with clinician's view that differences in staff and clients perception of client progress will decrease over time.
- The factor structure of the instruments supports the theory on which they are based. A confirmatory factor analysis of the CAI shows the 14 scales are unidimensional, reflecting a single construct for each competency. The factor structure of the SAS shows the 'Participation' factor causally influences the Performance factor (the combined 'developmental,' 'social,' and 'psychological' dimensions), as suggested by the theory.
- Scores are sensitive to change over time and early (one-month) change scores predict retention in treatment.

Next Steps: Overall, the CAI, CAS, and SAS provide theoretically-driven, psychometrically sound measures of client progress in TC treatment. They reliably differentiate client clinical changes during TC treatment and have the capacity to measure change, an important component of construct validity. The methods used to develop instruments for measuring client progress in treatment may be extended to modified TCs in a wide range of settings, for a growing diversity of clients.

Application for Recovery Measurement: While these measures were developed in the TC context they may be applicable more broadly (i.e., in other settings including outside of treatment services). The focus, however, is program/treatment specific so application for assessing recovery measures will require further evaluation.

MEASURES OF MENTAL HEALTH RECOVERY

The Recovery Self-Assessment (RSA) Instruments

Authors: O'Connell, Tondora, Croog, Evans, & Davidson, 2005

Source/availability: http://www.yale.edu/PRCH/tools/rec_selfassessment.html
and <http://www.ct.gov/dmhas/lib/dmhas/recovery/rsasummary.pdf>

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Purpose: To gauge the degree to which programs implement recovery-oriented practices.

Versions: Four versions of the RSA targeted to different groups: Person in recovery, Family member/significant other/advocate, direct care Provider, and agency CEOs and Directors.

Development: Multistage procedure including:

1. Extensive review of the literature on recovery from mental health and addiction produced by users and providers of mental health and addiction services, advocates, and researchers.
2. Identification of common principles of recovery and recovery-oriented systems (Davidson, O'Connell, Sells, & Staeheli, 2003) resulting in nine principles: Renewing hope and commitment; Redefining self; Incorporating illness; Being involved in meaningful activities; Overcoming the effects of discrimination; Assuming control; Becoming empowered and more involved in one's community and citizenship activities (e.g., voting, paying taxes); Managing symptoms and Being supported by others.
3. Generation of 80 items reflecting objective practices associated with the nine recovery-oriented systems principles.

Field test:

- Pilot test among 122 individuals at 10 DMHAS funded agencies
- RSA mailed to Directors at 231 DMHAS agencies (3312 surveys mailed) who were asked to distribute the survey to a provider who would then identify persons in recovery and family members to complete the instruments. The total sample consisted of 974 respondents from

82 agencies (29% response rate): 69 directors/CEOs, 347 providers, 329 persons in recovery, and 229 family/significant others or advocate.

Instrument: 36-item representing five empirically-derived factors (subscales):

- Diversity of Treatment Options (10 items): extent to which an agency provides linkages to peer mentors and support, a variety of treatment options, and assistance with becoming involved in non-mental health/addiction activities (12.24% of variance, $\alpha = .86$)
- Consumer Involvement and Recovery Education (7 items): the extent to which persons in recovery are involved in the development and provision of programs/services, staff training, and advisory board/management meetings, and community education activities (12.1% of variance, $\alpha = .86$)
- Life Goals vs. Symptom Management (6 items): the extent to which staff help with the development and pursuit of individually defined life goals such as employment and education (10.8% of variance, $\alpha = .76$)
- Rights and Respect (6 items): the extent to which staff refrain from using coercive measures, provide consumers with access to treatment records, and facilitate outside referrals (9% of variance, $\alpha = .71$)
- Individually-tailored Services (7 items) that reflect the extent to which services are tailored to individual needs, cultures, and interests, provided in a natural environment, and focus on building community connections (9% of variance, $\alpha = .75$)

Response scale: 5-point Likert scale response format from 1 (strongly disagree) to 5 (strongly agree) and not application (N/A).

Use: The RSA instruments are used in the service setting to provide mental health and addiction services agencies with individualized profile of their services that allows for comparison with others statewide or nationwide, and identifies service areas where the agency is doing well as well as areas where improvements are needed (both operationalized as scoring 1 standard deviation above or below the mean of other comparable agencies). The RSA instruments were developed and are used by the State of Connecticut and increasingly adopted by other state systems (as per the author).

Next Steps:

1. Examine criterion and construct related validity of RSA.
2. Individual reports/feedback are being prepared for each participating agency.

Application for Recovery Measurement: The series of measures was developed to assess recovery-oriented services at the systems or agency level. The multiple versions is a strength as it allows for comparison across stakeholder groups that may be useful for internal quality monitoring and service development.

Illness Management and Recovery Scales (IMR)

Authors/source: Mueser & Gingerich, 2005; Mueser, Gingerich, Salyers, McGuire, Reyes, and Cunningham, 2004.

Instrument contact:

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Background and Purpose: Recovery from chronic mental health conditions such as schizophrenia and other severe mental illness requires collaborative symptom management that involves the patient and doctor working together to help managing their illness, collaborating with treatment providers, and pursuing their recovery goals. The Illness Management and Recovery (IMR) program is an evidence-based practice designed to assist individuals with psychiatric disabilities develop personal strategies to manage their mental illness and advance toward their goals. The IMR scales were developed as a measure of illness management that integrates specific empirically supported strategies for teaching illness self-management into a cohesive treatment package based on two theoretical models: the transtheoretical model and the stress-vulnerability model of severe mental illness. The transtheoretical model proposes that motivation to change develops over a series of stages (precontemplation, contemplation, preparation, action, maintenance) and that facilitating change requires stage-specific interventions (Prochaska & DiClemente, 1984; Corrigan, McCracken, & Holmes, 2001; Miller & Rollnick, 2002). The stress-vulnerability model posits that the course and outcome of schizophrenia is determined by the dynamic interplay of biological vulnerability, stress, and coping (Zubin & Spring, 1977; Liberman et al., 1986). Biological vulnerability can be reduced by adherence to prescribed medications and reduction or avoidance of alcohol or drug use. The effects of stress on vulnerability can be reduced by improved coping skills, social support, and involvement in meaningful activities.

Development: Items were generated by IMR practitioners and consumers of services to tap all the critical self-management domains targeted by the IMR program with as few items as possible. Additional clinicians and consumers provided feedback about item selection and the wording of items and modifications were undertaken accordingly.

Instrument Description: Two versions of the instrument:

1. Client version
2. Clinician version

Items and Domains: Both versions of the IMR Scales, the Clinician Version and the Client Version, contain 15 items. The Scales are not divided into domains; rather, each item addresses a different aspect of illness management and recovery (e.g., progress toward goals, knowledge about mental illness, involvement with significant others and self-help, time in structured roles, impairment in functioning, symptom distress and coping, relapse prevention and hospitalizations).

Response scale: 5-point Likert scale with the response anchors varying dependent upon the item.

Scoring: Items are summed on the IMR Scales (separately) to form a single score for each version of the scale.

Intended Populations and Settings: The IMR Scales are intended to be used and were field tested among adults from diverse ethnic/racial backgrounds (Asian, Black or African American, White, Hispanic or Latino) who have been diagnosed with a serious mental illness, including those who have a co-occurring substance use disorder. Subgroup analyses have not been conducted to determine whether significant differences exist across ethnic/racial groups or among groups with different diagnoses.

Though field testing was conducted in an outpatient service setting, The IMR Scales are intended for use in an array of service settings including the criminal justice system, inpatient service settings, outpatient service settings, peer-run programs, and residential service settings.

Testing and Psychometric Properties:

Field Testing: Initial psychometric testing was conducted using responses from 50 adults with severe mental illness served in a large psychosocial rehabilitation agency and 20 clinicians. Participants (consumers and clinicians) completed the scales twice with an interval of two weeks between each administration.

Table 2. IMR Psychometrics

Version	Internal Consistency (Cronbach's Alpha)	Test-Retest r^*	Convergent Validity Pearson r	Convergent Validity Pearson r
Client	0.70	0.82	RAS = .38	CSI = .54
Clinician	0.71	0.78		

* Results are based on a 2-weeks interval between 1st and 2nd scale administration

Further testing and evaluation: Currently, the developers are examining the criterion validity of the IMR Scales by studying the relationship between the IMR ratings and hospitalization and employment in the context of an implementation study.

Current/Past Uses: The IMR Scales are currently being used to guide clinical practice and to evaluate the impact of the IMR program in research. Clinically, the consumer and clinician can both rate the consumer on progress and then compare results to discuss perceptions of progress in the program.

Quality Improvement Uses: If done quarterly (or some other regular interval), results can be fed back to clinicians and consumers to inform progress in IMR or other illness self-management training programs. The results can be used to track progress over time, and to compare between programs. This is currently being done in a statewide implementation of IMR.

Application for Recovery Measurement: Though developed in the mental health context, the Client version of the IMR is highly relevant to addiction recovery – with the exception of mental health specific domains such as psychiatric hospitalizations and medication issues though they may be relevant to the many individuals in addiction recovery who are dually-diagnosed with a mental health disorder. Because the tool currently lacks addiction specific domains, relevant items/domains would need to be added to maximize the adequacy of the instrument in the addiction recovery context.

Mental Health Recovery Measure

Authors: Young and Bullock, 2003

Instrument contact:

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Available from: Campbell-Orde, Chamberlin, Carpenter, & Leff, 2005b

Purpose: To comprehensively assess the process of recovery from serious mental illness as experienced by consumers, without relying on symptoms or symptom management measures.

Conceptual Framework: The domains and item content are based on a conceptual model of mental health recovery that was developed through grounded theory analysis (Glaser & Strauss, 1967) of qualitative interview data on the recovery experience from 18 individuals with psychiatric disabilities (Young & Ensing, 1999; Ralph et al., 2000).

Development: Initial 41-item scale was tested among > 200 mental health consumers in diverse service settings. Statistical work including comparing each item to the total reliability within a given subscale, principal components factor analysis and Rasch modeling (Rasch, 1980) resulted in the current 30-item version (Bullock & Young, 2003).

Instrument description:

- 30 items
- Response scale: 5-point Likert scale ranging from “strongly disagree” to “strongly agree”
- Seven domains (4 items per domain): Overcoming Stuckness, Self-Empowerment, Learning and Self-Redefinition, Basic Functioning, Overall Well-Being, and New Potentials, Advocacy/Enrichment; two items measure Spirituality but have not been established as a subscale

Scoring:

- Total/subscale scores are the sum of relevant
- Theoretical scale score range = 0 – 120
- Actual range in field testing (N = 215): 22 – 120, Total MHRM mean = 80 (SD=20)

Field Testing: Initial psychometric analyses were conducted on data from persons with psychiatric disabilities (N=180) drawn from diverse service settings. Additional analyses of the final 30 item measures were conducted on 279 individuals from five community mental health center sites and two community-based sites that provide peer support for mental health consumers.

Psychometric Properties:

Table 3. Mental Health Recovery Measure Psychometrics

Mental Health Recovery Measure	Internal Consistency (Cronbach's alpha)
Overall	0.93
Subscales	
Overcoming Stuckness	0.6
Self-Empowerment	0.82
Learning & Self-Redefinition	0.79
Basic Functioning	0.62
Well-Being	0.86
New Potentials	0.62
Advocacy/Enrichment	0.66

Test-retest reliability: N=18 assessed at one- and two-week interval (r=.92 and r =.91, respectively).

Validity

Relationship to Established Measures (Bullock & Young, 2003).

Table 4. Correlations between MHRM Total Score and Other Measures

Measure	R	N
MHRM and the Empowerment Scale (Rogers, Chamberlin, Ellison, & Crean, 1997)	.67	150
MHRM and the Conner-Davidson Resilience Scale (Connor & Davidson, 2003)	.73	150
MHRM and the Resilience Scale (Wagnild & Young, 1993)	.75	150
MHRM and the Community Living Scale (Smith & Ford, 1990)	.57	180

Relationship to Other Criteria:

- MHRM discriminates between groups of individuals at different levels of recovery based on participation in treatment or recovery programming (Bullock, Wuttke, Kleine, & Bechtoldt, 2002; Bullock & Young, 2003).
- MHRM demonstrate significant change (improvement) for individuals following completion of an evidence-based practice (the “Illness Management and Recovery” program – see earlier discussion) designed to promote recovery (Bullock et al., 2005).

Target Populations: The MHRM is intended for use and has been tested with adults diagnosed with a serious mental illness from several ethnic/racial groups.

Service Settings: The MHRM is intended for use and has been tested with consumers who receive services in the criminal justice system, inpatient, outpatient service, peer-run program, and residential service setting.

Ongoing Testing and Evaluation: Evaluation of MHRM as an outcome measure and normative data collection across different sites and with different mental health consumer populations.

Current/Past Uses: Used as an outcome measure of changes in mental health recovery for persons who are completing individual or group treatments designed to promote recovery.

Application for Recovery Measurement. The measure is short and psychometrically strong. Many of the items are explicitly phrased in terms of mental health recovery and some of the domains are specific to mental health (e.g., overcoming ‘stuckness’); thus qualitative work would be required to assess the feasibility of the scale in the addiction recovery context and to guide any necessary adaptation and addiction-specific item development.

Recovery Assessment Scale (RAS)

Authors: Giffort, Schmook, Woody, Vollendorf, & Gervain, 1995

Instrument contact:

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Availability: Campbell-Orde et al., 2005a

Purpose: Outcome measure for program evaluations.

Conceptual Framework: Based on a process model of recovery, the RAS attempts to assess aspects of recovery with a special focus on hope and self-determination.

Development : Narrative analysis of four consumers' recovery stories (Giffort, Schmook, Woody, Vollendorf, & Gervain, 1995) followed by review of the initial 39-item scale by 12 consumers resulting in the current 41-item scale (Corrigan, Giffort, Rashid, Leary, & Okeke, 1999).

Instrument Description:

- 41 items
- Five domains/subscales: Personal Confidence and Hope, Willingness to Ask for Help, Goal and Success Orientation, Reliance on Others, and No Domination by Symptoms. *Seventeen of the scale's items are not incorporated into the current factor structure.*
- A series of principal components exploratory factor analysis and confirmatory factor analysis (CFA) conducted to establish the factor structure of the RAS yielded a five-factor solution where the alpha ranged from .74 to .87 across factors; structural equation models to cross-validate the factors (Corrigan, Salzer, Ralph, Sangster, & Keck, 2004).
- Response scale: 5-point Likert scale ranging from 1 = "strongly disagree" to 5 = "strongly agree."

Intended population and settings: Intended for/tested among adults from diverse ethnic/racial backgrounds who have been diagnosed with a serious mental illness in two service settings: outpatient setting and peer-run programs.

Field Testing: The first test was conducted among 35 ethnically diverse consumers in a partial hospitalization program who had a diagnosis of serious mental illness, 3 or more hospitalizations in the past 2 years and were unable to work as a result of their mental illness (Corrigan et al., 1999). A

second field test to examine the RAS’s factor structure and the association between individual factors and specific symptoms was conducted among 1,750 ethnically diverse consumers participating in the Consumer Operated Services Program (COSP) Multi-site Research Initiative, individuals with a DSM-IV, Axis I diagnosis consistent with serious mental illness and a significant functional disability as a result from the mental illness (60.1% females; Corrigan et al., 2004).

Psychometric properties:

Reliability

Internal Consistency: Cronbach’s alpha =.93 (N=35)

Test-Retest Reliability: 2-weeks r =.88 (N=35)

Validity

Relationship to Established Measures of related constructs: The association of the RAS total score with five psychosocial variables (N=35) conceptually related to recovery was investigated: self-esteem (Rosenberg, 1965), self-orientation (Rogers, Chamberlin, Ellison, & Crean, 1997), quality of life (Lehman, 1983), social support (Sarason, Levine, Basham, & Sarason, 1983) and psychiatric symptoms (Lukoff, Liberman, & Nuechterlein, 1986); as shown below, the correlation were moderate to high (Corrigan et al., 1999).

Table 5. Pearson Correlation Coefficients Between RAS Total Score and Related Constructs

Scale	Correlation Coefficient
Rosenberg Self-Esteem Scale	0.55
Empowerment Scale (Self-Orientation)	-0.71
Social Support Questionnaire	0.48
Quality of Life Interview	0.62
Brief Psychiatric Rating Scale ¹	-0.44

Current/Past Uses: The RAS was one of the instruments used in a Federally funded multi-site study that examines the impact of consumer-operated services on consumers’ outcomes, when used in conjunction with traditional mental health services.

Application for Recovery Measurement: The instrument provides a good quantifiable overview of the individual’s psychological state and outlook in the recovery context; the inclusion of items that tap quality of life and purpose in life is a strength as these domains are critical to recovery and rarely included in recovery measures. The instrument lacks critical dimensions such as quality of living environment, issues related to employment and education, family and social relations. Therefore it is not likely to be useful to guide recovery-oriented services or to evaluate its outcomes in the absence of additional dimensions and should be regarded, instead as a measure an individual’s recovery ’orientation.’

¹ Does not meet Bonferroni Criterion for significance

MEASURES DEVELOPED FOR OTHER CHRONIC CONDITIONS

Identifying measures of recovery as related to chronic conditions other than SUD and mental health proved challenging. The construct of ‘recovery’ does not technically exist in relation to chronic conditions. This is not surprising as the cardinal trait of a chronic condition is that there is no cure although symptoms can be managed.

Reviewed below are two measures that exemplify the current state of measure development work in the area of chronic conditions other than SUD and MH. The first was developed in the specific context of diabetes although it is envisioned by the authors to be applicable to other conditions; the other is a large-scale multi-federal agencies effort to develop a tool to assess patient reported outcomes across chronic conditions. Additionally, we describe the World Health Organization’s Quality of Life instruments (WHOQOL) that are increasingly used in biomedical research (including mental health and addiction) worldwide to assess positive health outcomes across populations and provides an illustration of state of the art instrument development.

Measure of Resources and Support for Chronic Illness Self-Management

Authors: McCormack, Williams-Piehota, Bann, Burton, Kamerow, Squire, Fisher, Brownson, & Glasgow, 2008

Source/availability: The Diabetes Educator
<http://tde.sagepub.com/cgi/content/abstract/34/4/707>

Purpose: To develop an instrument to measure resources and support for self-management (RSSM) for the survey component of the evaluation of the Robert Wood Johnson Foundation’s Diabetes Initiative, a project designed to demonstrate the feasibility of self-management interventions on real world settings.

Methods:

- Review existing validated patient report instruments as the foundation on which to develop a measure reflecting a broad, ecological perspective of RSSM: the Patient Assessment of Chronic Illness Care (PACIC) instrument (Glasgow, Whitesides, Nelson, & King, 2005) and the Patient Activation Measure (PAM) (Hibbard, Mahoney, Stockard, & Tusler, 2005).
- Generate additional items/domains not addressed by existing measures
- Cognitive testing with small sample of convenience (N = 14) to determine clarity of instructions, wording of survey
- Select answer categories

- Multiple wave of pilot field test with successive wave incorporating revisions emanating from previous field test wave (e.g., deleting items showing a ceiling effect): $N_1 = 720$ and $N_2 = 957$, respectively
- Final RSSM scale consists of 17 items: 10 items that were altered from an existing scale, and 7 new items

Statistical examination of the psychometric properties of both the items and the overall scale:

- Items descriptives
- Confirmatory factor analysis
- Linear regression analyses to explore the relationship between overall scores on the RSSM scale and key following participant characteristics (e.g., gender, age, race, education level, self-reported health status, family history of diabetes, length of time since diabetes diagnosis).
- Linear and logistic regression models to test for a relationship between overall RSSM scores and self-management behaviors, controlling for demographics and to explore construct validity.
- Five-factor scale structure: (1) Individualized assessment; (2) Collaborative goal setting; (3) Enhancing skills; (4) Ongoing follow-up and support; and (5) Community resources.
- Adequate psychometrics including internal consistency and construct validity. The Cronbach alpha reliability scores of the 5 subscales range from .74 to .90.

Next steps: Test broader application of the instrument in self-management support and for primary care settings: Validate the instrument in other populations and among individuals with other chronic diseases (e.g., managing heart disease and stroke, weight loss and smoking cessation).

Application for Recovery Measurement: This measure in its current form is presented as an exemplar of chronic illness symptom management assessment as practiced outside of the addiction field. As substance abuse services are increasingly adopting a chronic care model, it is important to look to other biomedical disciplines that support symptom management through a continuum of care approach which is what this measure was developed to assess. The authors envision a broader applicability of the instrument for other chronic conditions. Substance abuse treatment providers and researchers may consider adapting the tool, in spirit if not exactly in substance, to the recovery-oriented continuum of care context.

Patient-Reported Outcomes Measurement Information System (PROMIS)

Author: PROMIS Cooperative group

Source: <http://www.nihpromis.org>

Background: Clinical outcome measures, such as x-rays and lab tests, have minimally immediate relevance to the day-to-day functioning of patients with chronic diseases such as arthritis, multiple sclerosis, and asthma, as well as chronic pain conditions. Often, the best way patients can judge the effectiveness of treatments is by perceived changes in symptoms and overall functioning.

Purpose: The PROMIS initiative established a collaborative relationship between the NIH and individual research teams through a cooperative agreement mechanism to:

- Develop and test a large bank of items measuring patient-reported outcomes such as pain and fatigue, and aspects of health-related quality of life across a wide variety of chronic diseases and conditions;
- Create a computerized adaptive testing system that allows for efficient, psychometrically robust assessment of patient-reported outcomes in clinical trial research involving a wide range of chronic diseases; and
- Create a publicly available system that can be added to and modified periodically and that allows clinical researchers to access a common repository of items and computerized adaptive tests.

Approach:

- Use archival data of extant datasets to better understand the dimensional structure of items that tap one of the five selected domains;
- Inform the revision of items in the item library;
- Inform the identification of the most useful response sets; and
- Guide new item construction in preparation for the first wave of PROMIS testing.

Domain framework: PROMIS investigators developed a domain framework for self-reported health. The three key domains are physical, social and mental health (*see Figure*).

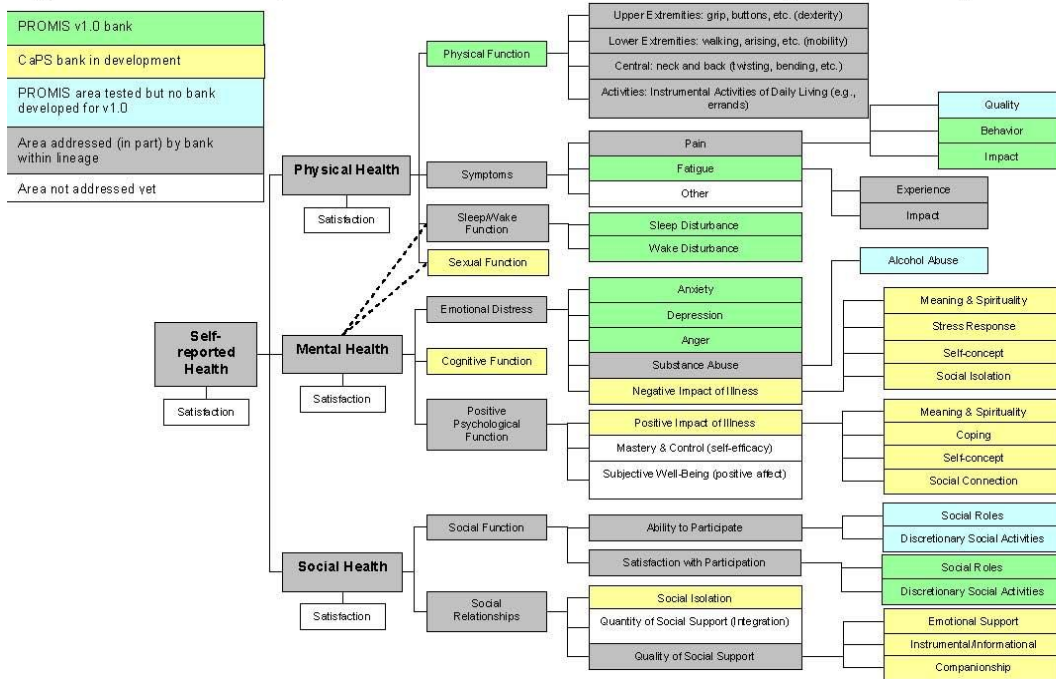
Domain/subdomain definitions have been created thus far for *global health, physical function, fatigue, pain, emotional distress (including depression, anxiety, and anger), and social health (social function and social support)*.

Six phases of item development:

1. Identification of existing items: Systematic search for existing items in currently available scales from extant datasets with self-report data on the PROMIS core domains: 11 datasets selected for initial analysis;
2. Item classification and selection using IRT analysis;
3. Item review and revision by statistician and the appropriate domain workgroup;
4. Focus group to confirm domain definitions, and to identify new areas of item development for future PROMIS item banks;
5. Cognitive interviews with individual items; and
6. Final revision before field testing.

Field testing of candidate items: Data were collected from the U.S. general population and multiple disease populations using full-bank administration and block administration: the former allows for evaluation of dimensionality and calibration within item banks, the latter permits an evaluation of associations between domains. Each item was administered to at least 900 respondents from the general population and 500 respondents with a chronic medical condition.

Appendix A: Patient Reported Outcomes Measurement Information System (PROMIS) Domain Framework



Sampling and sample:

- Internet-based sampling and data collection conducted primarily by YouGovPolimetrix (<http://www.polimetrix.com>, also see <http://www.pollingpoint.com>).

-
- Random sampling of internet based representative panel members selected using the following criteria: gender (50% female), age (20% in each of 5 age groups ranging from 18 to 75+), race/ethnicity (10% black and Hispanic), and education (10% less than high school graduate).
 - Wave 1 sample (N = 21,133) represented the general population and a clinical sample of persons heart disease (N = 1,156), cancer (N = 1,754), rheumatoid arthritis (N = 557), osteoarthritis (N = 918), psychiatric illness (N = 1,193), chronic obstructive pulmonary disease (N = 1,214), spinal cord injury (N = 531), and other conditions (N = 560). Of that total sample, 7,005 were used for the full bank administration, and 14,128 for block testing.

Instrument properties:

- Recall: “The past 7 days”
- Response options: all domains use five response options that vary by domain (e.g., 1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much)
- Raw and scale scores, reliability

Scoring:

Scoring algorithm from PROMIS software developed from the item response theory (IRT) model and scoring table available in PROMIS manual to convert raw score to T score are available online to registered users (registration is free) at <http://www.assessmentcenter.net/ac1/>.

Current status of Instruments:

- The item bank v1 is available for each of the PROMIS domains and subdomains for clinical investigator to create assessments;
- For each domain, a score will be produced on the same common (Theta) metric which has been converted to a T-distribution based on the United States general population; and
- Internet or computer administration is recommended since it was the administration mode of the Wave I field test.

Next steps:

Items successfully screened in Wave I will be subjected to innovative scale construction procedures.

Assessment Center SM is a dynamic application that will allow researchers to centralize all research activities. It includes features that promote instrument development, study administration, data management, and storage of statistical analysis result. Anyone may utilize Assessment Center SM at <http://www.assessmentcenter.net/ac1/>.

Application for Recovery Measurement: This is an extremely promising initiative because of the breadth of the domains and subdomains included in the model, the inter- and multidisciplinary approach, and the scientific rigor with which it is being carried out. The applicability of the measures across chronic conditions is another strength as the majority of substance dependent persons also report a co-occurring physical and/or a mental health condition. The conceptual framework guiding the effort is highly relevant to addiction recovery although important domains such as living environment, education and employment are missing and should be included to maximize relevance to addiction recovery. At this writing the extensive and ambitious project is still unfolding and some aspects of it that will be critical to quantifying addiction recovery outcomes are not completed, most notably the substance use items and the satisfaction items for each domain. Therefore the PROMIS initiative may represent an appropriate starting point to develop a comprehensive measure of addiction recovery that would be applicable across contexts (specialty care, recovery support services) and its progress should be followed closely as it develops.

The World Health Organization Quality of Life Instruments (WHOQOL)

Authors: World Health Organization Quality of Life Group Bonomi & Patrick, 1997; Bonomi, Patrick, Bushnell, & Martin, 2000b; The WHOQOL Group, 1993; The WHOQOL Group, 1996; WHOQOL Group, 1994; WHOQOL Group, 1998a; WHOQOL Group, 1998b.

Source/availability: http://www.who.int/mental_health/media/68.pdf

Background and Purpose: Quality of life (QOL) is an important diagnostic and outcome criterion in biomedical research and it is also of prognostic value in clinical practice; QOL incorporates the individual's subjective view and illuminates domains not captured by traditional symptom measures. The World Health Organization Quality of Life Group was formed to develop a generic, psychometrically strong, cross-culturally valid measure of QOL that would be broadly applicable across disease types, varying severity of illness, and diverse socioeconomic and cultural subgroups. The instrument would be used to: (a) Evaluate the effects of program interventions on QOL; (b) Compare QOL across countries; (c) Compare subgroups within countries; and (d) Measure change over time in response to changes in life circumstances. The WHOQOL research group defines QOL as *individuals' perceptions of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns* (World Health Organization, 1997).

Instrument description: The WHOQOL is a 100-item self-report instrument consisting of 24 facets or subscales that tap six life domains (Physical, Psychological, Independence, Social, Living Environment, and Spirituality) plus overall QOL/health (see Table below). Four items represent each of the 24 facets for a total of 96 items, and one additional facet (4 items) pertains to global QOL and general health. All WHOQOL domains are important to QOL across cultures (Power, Harper, & Bullinger, 1999; Anderson, Aaronson, Bullinger, & McBee, 1996). The WHOQOL-100 affords separate facet and domain scores, but no total score. Domain and facet scores are scaled in a positive direction where higher scores denote higher QOL (after recoding where needed).

WHOQOL-100: Six Domain Scores + Overall QOL Satisfaction Rating

ASSESSES How much/completely/often/good/satisfied...

1. **Physical capacity** (Alpha=.83) 3 Facets: Pain, energy, sleep.
2. **Psychological health** (Alpha=.86) 5 Facets: Positive feelings, negative feelings, self-esteem, body image, concentration/thinking/learning
3. **Social relations** (Alpha = .82) 3 Facets: Relationships, social support, sexual activity
4. **Independence** (Alpha = .86) 4 Facets: Mobility, work capacity, activities of daily living, reliance on medications
5. **Living Environment** (Alpha=.91) 8 Facets: Safety, home, finances, access to social care, access to new information, opportunity for leisure, environment, transportation
6. **Spirituality** (Alpha=.87) single facet
7. **Overall QOL satisfaction** rating (4 items)

Because the WHOQOL-100 is multidimensional (measures a wide range of quality of life areas) and is subjective (responses are obtained from patients themselves), it meets the criteria of a quality of life instrument. The instrument manual provides administration protocols, scoring algorithms, guidance to interpret effect size, and published US population norms for healthy and chronic condition populations (Bonomi & Patrick, 1997). It takes about 25 minutes to administer.

Response scale: All items are rated on a 5-point scale of experiences in the last two weeks. Four types of scales are used: intensity (e.g., How much do you enjoy life?), capacity (e.g., How well are you able to?), frequency (How often?), and evaluation (e.g., How satisfied are you with?).

Development: As described by the WHO (http://www.who.int/mental_health/media/68.pdf) and shown below, the WHOQOL measurement system was developed using a standard cross-cultural approach to item generation and reduction. First, focus groups were conducted in each of the 15 collaborating countries to identify general issues relevant to QOL. A comprehensive list of over 1,800 items was reduced to 1,000 by eliminating semantically redundant items. Based on their experience in the initial qualitative phase of the project, researchers in each of the field centers ranked the remaining 1,000 items by order of importance, which resulted in a 236-item pilot version. The 236-item instrument underwent pre-testing in the original 15 countries, and resulted in the current 100-item version: the WHOQOL-100 instrument.

Table 6. Development of the WHOQOL Instruments

Stage	Method	Products	Objectives
Concept Clarification	International Expert Review	Quality of life definition study protocol	Establish an agreed upon definition of quality of life and an approach to international quality of life assessment.
Qualitative Pilot	Expert Review Focus Groups	Definition of domains and facets; Global item pool.	Explore quality of life concept across cultures; Item generation.
Development Pilot	Administration of WHOQOL Pilot Form in 15 field countries to 250 patients and 50 “healthy respondents”	300-item standardized questionnaire	Refine the WHOQOL structure; Reduce the global question pool.
Field Test of the WHOQOL-100	Series of smaller scale studies involving clear and homogenous populations, longitudinal design and parallel use of other national /international QOL measures.	Common 100-item pool; Standardized and cross-nationally equivalent response scales.	Further establish psychometric properties of the WHOQOL.
Development of the WHOQOL - BREF	Analysis of data from the WHOQOL-100	Abbreviated 26-item assessment	Develop a brief version of the WHOQOL-100 for use in large studies, audit and clinical work, where use of a longer questionnaire is not practicable.

Field testing: Since 1994, the WHOQOL-100 has undergone testing in each of the 15 countries. The United States WHOQOL-100 version was field tested in a sample of US 443 adults (chronically ill: N = 251; healthy N = 128; and childbearing N = 64 Bonomi et al., 2000b).

Instrument Properties:

The WHOQOL is psychometrically sound across countries and cultures and among both ill and well persons (Skevington, 1999; Power et al., 1999). The U.S. version has good psychometric properties among healthy and chronically-ill persons including internal consistency (see Table 6), construct validity, conceptual structure, reproducibility, and responsiveness to change in clinical conditions (Bonomi, Patrick, Bushnell, & Martin, 2000a). The measure discriminates between ill and well persons (Ulas, Akdede, Ozbay, & Alptekin, 2008), between different levels of symptoms (Sakthong, Schommer, Gross, Sakulbumrungsil, & Prasithsirikul, 2007) and between different clinical conditions. (De Girolamo et al., 2000; Struttman et al., 1999). Used in prospective studies *among substance users*, it showed good sensitivity to change (Passey, Sheldrake, Leitch, & Gilmore, 2007). Moreover, across populations, the WHOQOL has been found practical, easy to administer and well accepted by respondents (Wirnsberger et al., 1998; Saxena, Chandiramani, & Bhargava, 1998; Tazaki et al., 1998).

Psychometric properties of US version (Bonomi & Patrick, 1997; Bonomi et al., 2000b)

- Internal consistency (alpha range: 0.82-0.95 across domains – see Table 6)
- Test-retest: ICC range: 0.83-0.96 at 2-week retest interval.
- Sensitivity to change: Responsive to change in clinical conditions, as evidenced by predicted score change (effect size) in women after childbirth.
- Construct validity was demonstrated by (1) its correlation with the Short Form-36 (Stewart & Ware, 1989; Ware & Sherbourne, 1992) and Subjective Quality of Life Profile (Gerin et al., 1989; Gerin, Dazord, Cialdella, Leizorovicz, & Boissel, 1991) and (2) its ability to discriminate between the diverse samples in this study.

The WHOQOL BREF:

Recognizing the need for a brief instrument for use in clinical practice and longitudinal research, the WHOQOL group developed the *WHOQOL-BREF* (World Health Organization Quality of Life Group WHOQOL, 1998), a 26-item abbreviated version of the WHOQOL-100. Using data collected for the WHOQOL-100 field trials, items for the BREF were selected for their ability to explain a substantial proportion of variance within their parent facet and domain, for their relationship with the overall WHOQOL model and for their discriminant validity (World Health Organization Quality of Life Group WHOQOL, 1998). Analysis of these extracted items showed that a four-factor structure best fitted the data whereby spirituality is subsumed under the psychological domain and independence under physical health. Based on these results, the WHOQOL-BREF was developed with four QOL domains: physical, psychological, social and environment and yields a score for each domain. The BREF contains one item from each of the 24 QOL facets from the WHOQOL-100, plus two ‘benchmark’ items from the general facet on overall QOL and general health (not included in the scoring) and uses the same response format and categories as does the larger WHOQOL 100.

Psychometric Properties were assessed in an international study (including the US) among chronic conditions, primary care and general population adults (Skevington, Lotfy, & O’Connell, 2004). The instrument was found to be a sound, cross-culturally valid assessment of QOL with good to excellent psychometric properties. Internal consistency Cronbach’s alpha >0.7 (except for the 3-item social domain where alpha in the US was .69). Alpha analyses carried out by systematically removing then replacing each item showed that all 26 items made a significant contribution to the variance in the BREF; good discriminant validity as per the instrument’s ability to distinguish sick and well participants; sensitivity to change; and confirmation of the four factor model. The WHOQOL-BREF has general population norms and has been used among opiate dependent persons with and without psychiatric axis-I disorder (Bizzarri et al., 2005); and alcohol dependent persons (da Silva Lima, Fleck, Pechansky, de Boni, & Sukop, 2005). BREF domain scores correlate around 0.9 with the WHOQOL-100 domain scores (World Health Organization, 1997).

Uses: The WHOQOL instruments are the most widely used transcultural QOL measures for adults, currently available in over 40 languages (Ceremnych, 2004). Both versions of the WHOQOL are increasingly used in biomedical research worldwide: a March 2008 Pubmed search revealed that the

number of English language peer-reviewed studies using the WHOQOL increased six-fold in the past five years, from 17 in 2002 to 101 in 2007 (an underestimation of this growing trend as non-English language studies are excluded). In the past decade, the WHOQOL has been used in cross-sectional and longitudinal studies worldwide across a wide range of populations including diverse community-based healthy populations (Lin et al., 2002; Scocco, Rapattoni, & Fantoni, 2006; von dem Knesebeck, David, Bill, & Hikl, 2006; Wang et al., 2000) and persons affected by a broad range of chronic conditions - e.g., epilepsy, diabetes, chronic pain and COPD (Heald et al., 2004). (Andenaes, Moum, Kalfoss, & Wahl, 2006; Cotrufo et al., 2005; Gromov, Mikhailov, Vasserman, Lyytik, & Flerova, 2002; Lundgren, Dahl, Melin, & Kies, 2006; Muller, Schwesig, Leuchte, & Riede, 2001; Pibernik-Okanovic, Szabo, & Metelko, 1998; Skevington, Bradshaw, Hepplewhite, Dawkes, & Lovell, 2006; Skevington, Carse, & Williams, 2001). Most relevant to this report, the WHOQOL is increasingly used among persons with mental health disorders (Angermeyer, Holzinger, Matschinger, & Stengler-Wenzke, 2002; Dogan et al., 2004; Gorna, Jaracz, & Rybakowski, 2005; Kunikata, Mino, & Nakajima, 2006; Sim et al., 2006; Sim, Chua, Chan, Mahendran, & Chong, 2006; Skevington & Wright, 2001; van de Willige, Wiersma, Nienhuis, & Jenner, 2005; Yau, Chan, Chan, & Chui, 2005), substance use disorders (da Silva Lima et al., 2005; Donovan, Mattson, Cisler, Longabaugh, & Zweben, 2005; Dunaj R. & Kovác D, 2003; Ginieri-Coccosis, Liappas, Tzavellas, Triantafillou, & Soldatos, 2007; Gunther, Roick, Angermeyer, & Konig, 2007; Padaiga, Subata, & Vanagas, 2007; Pal, Yadav, Mehta, & Mohan, 2007; Passey et al., 2007), including those dually-diagnosed with a psychiatric diagnosis, (Bizzarri et al., 2005) and among HIV+/HepC+ persons (Sebit et al., 2000; Belak Kovacevic, Vurusic, Duvancic, & Macek, 2006; Chandra, Deepthivarma, Jairam, & Thomas, 2003; Chandra et al., 2006; Fang, Hsiung, Yu, Chen, & Wang, 2002; Hsiao, Chao, Tsai, & Chuang, 2004; Hsiung, Fang, Chang, Chen, & Wang, 2005; Lau, Tsui, Patrick, Rita, & Molassiotis, 2006; Marcellin et al., 2007; Preau, Apostolidis, Francois, Raffi, & Spire, 2007; Wig et al., 2006; Yen et al., 2007; Yen et al., 2004; Zimpel & Fleck, 2007). Across studies and populations, the WHOQOL has proven to be a feasible and valid measure that is sensitive to change (Passey et al., 2007).

Application for Recovery Measurement: *The WHOQOL was recently suggested as a measure of recovery by a panel of SUD researchers, clinicians and persons in recovery* (Belleau et al., 2007). Moreover, in Connecticut, the first State to adopt a recovery-orientation in 1999,² the WHOQOL was selected by persons in recovery from among five well-being measures as most relevant to their experiences and needs, resulting in its inclusion in the State's consumer survey (personal communication, Mnachi Kikoo, Assistant to Dr. Thomas Kirk, Commissioner of the Connecticut Department of Mental Health and Addiction Services, 2/15/2008).

There are several reasons why the WHOQOL may constitute a promising starting point to develop a measure of recovery.

1. It assesses domains that are highly relevant to recovery (Valderrama-Zurian, 2009) including dimensions that are not typically assessed in other QOL measures – e.g., spirituality and living environment. SUDs affect a broad range of areas of functioning - vocational, social/familial, physical and mental health, cognitive, residential status and access to services

² <http://www.ct.gov/dmhas/site/default.asp>

- (American Psychiatric Association, 1994; Chaturvedi & Desai, 1997; Laudet, Magura, Vogel, & Knight, 2000; Maisto & Mc Collam, 1980), domains where improvement is needed for recovery to take place. Most recovery definitions, be it from persons in recovery (Laudet, 2007), Federal agencies (Center for Substance Abuse Treatment, 2006), independent panels (Belleau et al., 2007), or researchers (McLellan et al., 2005) either explicitly or implicitly include the concept of quality of life. The WHOQOL domains largely coincide with White et al's 'recovery zones': physical, psychological, relational, lifestyle and spiritual (White, 1996; White et al., 2005) and with that of the NIH PROMIS initiative (see description earlier) although the latter excludes living environment and spirituality, two dimensions that are likely to be critical to recovery.
2. Unlike many other measures that focus on uncovering problems or negative indicators - e.g., limitations in functioning- the SF-36 (Ware & Sherbourne, 1992), the WHOQOL is a balanced assessment of QOL, where both positive and negative aspects of life are considered. The WHOQOL is a multidimensional measure that seeks to capture overall QOL as defined by WHO (see earlier). The measure inquires *not only* about functioning *but also* about satisfaction with functioning, a prognostic indicator of sustained abstinence (Laudet, Becker, & White, 2009). This overall measurement approach is thus well-suited to the broader conceptualization of recovery and to a multi-system of care context.
 3. For the purpose of developing a recovery measure, the WHOQOL has several advantages in addition to its relevance to recovery: (a) The measure results from over a decade of cross-cultural psychometric and field validation conducted by WHO and others across diverse countries, cultures and subpopulations (health and chronically ill); (b) unlike some other QOL measures - e.g., the SF series (Stewart & Ware, 1989), the WHOQOL is in the public domain, freely available in over 40 languages with national population norms among healthy and ill populations, making it a cost-effective measure that is already broadly used and accepted worldwide. Finally, there are standardized procedures for adapting the WHOQOL to the needs of specific populations, maximizing its relevance and usefulness.

Need for Recovery-Specific Module: Measures are most useful to assess change when they are sensitive to the culture and context of the condition or group for which they are designed, reflecting the many life areas that are affected and relevant to that group (Hubley & Palepu, 2007; Adair et al., 2007; Guyatt, King, Feeny, Stubbing, & Goldstein, 1999). The WHOQOL was developed to be broadly applicable across disease types, varying severity of illness, and diverse socioeconomic and cultural subgroups (Bonomi & Patrick, 1997). While there are QOL aspects that are universal (Power et al., 1999), specific medical or living conditions have a specific impact on QOL and *therefore require that relevant dimensions be incorporated into a comprehensive QOL measure for that group* (De Vries, Seebregts, & Drent, 2000; Anderson et al., 1996; Puhan et al., 2007). In active addiction, many substance users live in an environment where infectious disease, crime, and violence are highly prevalent; socioeconomic conditions are often poor and they experience considerable instability in many aspects of their lives (Hubley & Palepu, 2007). Improvement in all the domains that are affected by active addiction are in many ways what constitutes recovery. In addition to the six WHOQOL domains, recovery specific

dimensions that may emerge include having a sense of future (Valderrama-Zurian, 2009), having direction or goals (Laudet, 2007), the desire to give back (Kaskutas, Ammon, Oberste, & Polcin, 2007), overcoming stigma, discrimination, and feelings of shame and guilt, and gaining a sense of freedom and empowerment. Co-occurring mental health issues and/or infectious disease are likely to be relevant to a sizable portion of persons in recovery but may not require that specific dimensions be developed as psychological functioning is among the WHOQOL domains and there is a WHOQOL-HIV already developed.

NOTE ON THE WHOQOL INSTRUMENTS:

Age and Condition Specific Supplemental WHOQOL Modules

1. As generic QOL is gaining importance in clinical practice and research worldwide, the WHO and independent researchers have developed subpopulation-specific adaptations of the WHOQOL to maximize its usefulness and relevance in specific settings. These modules were developed through a process similar to that used for the WHOQOL 100, consisting of qualitative preliminary work followed by item reduction and psychometric work done through large-scale field testing. These modules include the WHOQOL-OLD (Fleck, Chachamovich, & Trentini, 2006; Fleck, Chachamovich, & Trentini, 2003; Power, Quinn, & Schmidt, 2005; Winkler, Matschinger, & Angermeyer, 2006), the WHOQOL-HIV (O'Connell, Saxena, Skevington, for the WHOQOL-HIV Group, 2004; O'Connell K. et al., 2000; O'Connell, Skevington, & Saxena, 2003; Starace et al., 2002; WHOQOL HIV Group, 2003; WHOQOL HIV Group, 2004), a WHOQOL adaptation for persons living in war-like conditions (Giacaman et al., 2007), and condition-specific adaptations for persons with vision impairments (Dandona, Dandona, McCarty, & Rao, 2000), hemodialysis patients (Yang, Kuo, Wang, Lin, & Su, 2005; Yang, Kuo, Wang, Lin, & Su, 2006) and individuals with chronic pain (Skevington, 1998; Mason, Skevington, & Osborn, 2004). Across studies, researchers have identified five to twelve condition-specific dimensions that are added to the WHOQOL to maximize its relevance to a given subgroup (Starace et al., 2002; Lucas Carrasco, 2007; Yang et al., 2005; Yang et al., 2006). For example, five HIV/AIDS-specific dimensions were added for the WHOQOL-HIV: HIV symptoms, social inclusion, death and dying, forgiveness, and fear of the future (O'Connell et al., 2004; O'Connell K. et al., 2000; O'Connell et al., 2003; WHOQOL HIV Group, 2003; WHOQOL HIV Group, 2004).
2. WHOQOL Importance Items: The WHOQOL Group also developed a companion instrument consisting of 32 items assessing the *importance* of each of the facets of the WHOQOL-100. These Importance items have not been used in scoring the WHOQOL instruments, but are potentially useful in examining differences among different population groups. In particular for the present context, the Importance Items would help elucidate the specific dimensions of QOL that are critical to recovery and speak to whether the phenomenology of recovery is captured adequately by the WHOQOL or whether an additional recovery specific module ought to be developed (see above, Note #1).

SUMMARY AND RECOMMENDATIONS

Our primary finding is not surprising: *The addiction field currently lacks a dedicated measure of recovery* though all stakeholder groups recognize the urgent need for such a tool. Currently, addiction professionals who seek to quantify systems and organizational performance outcomes are using instruments developed in the mental health field (e.g., the RSA instruments) or in other biomedical disciplines (e.g., WHOQOL). With a few exceptions (e.g., the WHOQOL Instruments), most of the measures reviewed here have not been used longitudinally so that their ability to detect change over time is unknown.

The measures reviewed in this report share several characteristics in terms of their development and substance. Most result from an intensive effort combining qualitative work with quantitative analyses (e.g., item reduction, examination of factorial structure) using large-scale field testing procedures. Many are the product of collaboration between multiple stakeholder groups, most of which involve representatives of the group of individuals whose experience is being measured in the tool under development. Finally, all measures are multidimensional and there is broad consensus across measures in terms of the dimensions that ought to be included in a recovery measure, regardless of the condition one is recovering from.

Findings from this project suggest that the desired outcomes of illness management for any chronic condition, that is, wellness or ‘recovery,’ is consistent with the World Health Organization’s (WHO) conceptualization of health as a positive resource rather than the mere absence of symptoms (World Health Organization, 1985). The emerging empirically based consensus (Belleau et al., 2007; Laudet, 2007) is that addiction recovery is a multidimensional construct consisting of the many life areas that are impaired by active substance use typically measured by such widely used instruments as the Addiction severity Index -ASI - (McLellan et al., 1992). Several addiction experts have noted important considerations for measuring recovery from substance use disorders. For example, in a recently issued comprehensive report on *Sustained Recovery Management*, the United Nations’ Treatnet Group developed a *recovery capital model* that consists of eight domains: mental and physical health, family and social supports, safe housing/healthy environment, peer-based support, employment and resolution of legal issues, vocational skills and educational development, community integration/cultural renewal, and (re)discovering purpose and meaning in life (Treatnet, 2008). Both individual status on these domains and the individual’s satisfaction with each domain of functioning ought to be assessed to maximize the clinical relevance of the measure.

In the absence of a dedicated measure of addiction recovery, the Treatnet group recommends using the ASI and the WHOQOL to assess these key domains:

1. Maintenance of abstinence or reduction in substance dependence;
2. Improvement in personal and social functioning;
3. Improvement in mental and physical health;

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4. Reduction in risky behavior that could affect health; and
 5. Overall improvements in increasing access to livelihoods assets and recovery capital.

Changes in Family and Community Recovery Capital

Because treatment is a critical part of recovery initiation for most, the development of addiction recovery measures must consider existing measures, such as SAMHSA's NOMs. Of note, existing measures, especially the NOMs, the WHOQOL and the PROMIS initiative, may represent suitable starting points to develop a dedicated measure of addiction recovery. Condition-specific measure development efforts in other fields (see WHOQOL section) have shown the feasibility of capitalizing on existing an psychometrically sound instrument to assess outcomes for specific populations.

In summary, the addiction field currently lacks a measure of addiction recovery. The emerging framework, Recovery-oriented systems of care (ROSC) *is outcome-driven, research-based and requires ongoing monitoring and feedback for systems improvement* (Center for Substance Abuse Treatment, 2006; Clark, 2008). Therefore the absence of recovery measures is likely to hinder the ongoing systems transition to a recovery-oriented approach that will require the capacity to measure outcomes for both internal purposes (quality monitoring and improvement) as well as for external accountability purposes. *To maximize its usefulness to Recovery-Oriented Systems of Care (ROSC), an addiction recovery measure is critically needed and must have the following properties:*

Multidimensionality:

- Sound psychometric properties including the ability to detect change over time;
- Brevity to be feasible for repeated administration, especially in the context of 'concurrent recovery monitoring' - CRM - (McLellan et al., 2005); and
- Applicability across populations in terms of gender, age, cultural background, recovery 'path' and recovery stage.

To accomplish this objective, next steps should include:

- *Identify key addiction recovery 'ingredients' - domains that are broadly applicable to persons in recovery:* Conduct qualitative work (focus groups and a small number of individual interviews) on the phenomenology of addiction recovery among diverse groups in terms of recovery 'path,' duration, gender, age, ethnic/cultural background and substance use history;
- *Start by capitalizing on existing measures that result from extensive psychometric and field testing work:* Assess the feasibility of existing measures (e.g., the WHOQOL, PROMIS) to the recovery experience and to identify domains that are not covered or not covered adequately;
- *Develop addiction-recovery specific items using standardized measure development techniques:* Whether an existing measure emerges as an appropriate starting point, a very likely possibility, or it is determined that a new instrument must be developed, look to the methods described in this

report to develop a comprehensive yet concise number of items that provide coverage of the breath of experience for a given domain;

- *Assess the psychometric properties of the resulting instrument:* In this regard, it is important to keep in mind that recovery is a long-term dynamic process so that the measure's *ability to assess change over time*, to detect improvement (or deterioration) in discrete domains as well as overall will be a critical property of any addiction recovery measure to guide service development and to evaluate recovery-oriented services and supports; and
- *Involve multiple stakeholder groups:* persons in recovery whose experiences and outcomes would be the target of measurement are of course the most important source of information to develop a recovery measure. However, because a recovery instrument is likely to be used in recovery services and support settings for both internal quality monitoring and external accountability, other stakeholders must be included in the measure development effort, especially service providers and service payers.



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