

DS2000+ Outcomes Measurement and Reporting Module

Recommendations for Domains, Data Elements, and Instruments

Report from the Technical Expert Workgroup ¹

March, 2006

Development Process for Domains, Data Elements, and Instruments

Workgroups of behavioral health stakeholders—consumers, family members, providers, state mental health agencies, and managed behavioral health care organizations—recommended domains and data elements for measuring outcomes in behavioral health. These were reviewed by a technical expert workgroup (TEW) that recommended they be reduced in number; this task was carried out by TEW members with expertise in the content of outcomes measurement and reporting systems. The content experts made every effort to preserve the stakeholders’ recommendations by eliminating redundancy and grouping items with similar implications for outcomes measurement. The content experts then recommended instruments to measure the domains and data elements. In the tables below are the recommended domains, data elements, and instruments along with explanatory notes.

Outcomes and Performance Indicators

The DS2000+ Outcomes Measurement and Reporting Module is intended to measure person-level outcomes, defined as changes in a person’s health and mental health status, behavior, functioning, etc. as a result of an intervention or treatment. Achievement of many of the outcomes listed below requires that culturally competent services and resources are available in a community, e.g., living in a safe affordable home requires the community to have affordable housing available. Since these issues are assessed by measuring system performance indicators rather than person-level outcomes, they are not addressed here.

Domains

The domains recommended by the content workgroup are:

- Self Care: General Health and Co-morbidity
- Self Care: Alcohol and Substance Use/Abuse
- Psychological Symptoms
- Behavior and Functioning
- Relationships and Social Support
- Family Functioning

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- Adverse Events and Negative Outcomes
- Engagement in Treatment
- Quality of Life
- Recovery

Data elements

The recommended data elements are presented as constructs indicating positive change (e.g., improvement in general health, decrease in substance use, reduction in or absence of symptoms) to emphasize the goals of progress and recovery. Some of these constructs are readily measured by change in scores on whole instruments, sections of instruments, or single questions (e.g., decrease in alcohol use by a lower score on the CAGE; reduction in overall symptoms by a lower score on the Brief Psychiatric Rating Scale; reduction in specific symptoms by lower scores on applicable items of the Symptom Checklist-90-R). Other constructs, however, are not yet well defined or operationalized (e.g., improvement in self-management of medical/somatic conditions) and the field lacks instruments that correspond precisely. Nevertheless, the content experts believe that it is essential to enunciate the constructs so that the process of refinement and instrumentation can proceed.

Instruments

The workgroup is aware that many instruments are available for measuring outcomes. Those cited were selected because they have acceptable psychometric properties; other instruments could be added upon recommendations from the field, as instruments currently under development are shown to have acceptable psychometric properties, e.g., instruments currently being developed through CMHS data infrastructure grants or specifically for measuring recovery. The content experts recommended developing procedures for adding instruments as they become available. However, consistency in the use of recognized gold standard instruments would facilitate longitudinal assessments of outcomes across treatment programs nationally. A webpage on the main DS2000+ Online site is currently available to host discussions and facilitate feedback on instruments.

The current plan for the DS2000+ Outcomes Measurement and Reporting Module is to provide users with a choice of instruments for measuring outcomes. In this way, states, agencies, programs, and providers who now measure outcomes will not have to change their current practices and those new to outcomes measurement will have a variety of options to meet their needs. The content experts recommend developing a process for recording experience with use of these instruments, sharing data for psychometric testing, and maintaining a repository of instruments and their characteristics. They also recommended developing a cross-walk to relate results on commonly used instruments and determine benchmark scores to compare the magnitude of change and the quality of the outcome.

Because of the lack of correspondence noted earlier between most data elements and instruments, the content experts recommended instruments by domain. In some cases, only some sections of an instrument are applicable to a particular domain; hence, some instruments appear under several domains. We indicated the sections most applicable to each domain, but users may

certainly employ the entire instrument. We also indicated whether an instrument is in the public domain (PD) or proprietary (Pr). We also indicated whether an instrument is used by Massachusetts (MA), Ohio (OH), or Washington (WA), states that have already implemented web-based outcomes measurement systems.

The workgroup recommended instruments for measuring outcomes for both adults and children/youth. In the tables below, instruments for children/youth that are to be completed by children/youth are indicated by [C]. Instruments for children/youth to be completed by parents or guardians are indicated by [C,P] and those to be completed by teachers, providers, or mental health workers are indicated by [C,T].

We have cited references for the instruments the first time they are mentioned. Instruments in the public domain or provided by their authors are available on Decision Support 2000+ Online (www.ds2kplus.org) on the Outcomes Measurement Workgroup Homepage.

Data Standards for Measuring and Reporting Outcomes

The domains, data elements, and instruments are presented in the format of the DS2000+ Data Standards in Appendix 1.

Domains, Data Elements, and Instruments

Domain	1. Self Care: General Health and Co-morbidity ^a
Data Elements /Constructs	1.1. improvement in co-morbid medical/somatic condition(s) ^b 1.2. improvement in general health ^{c,d} 1.3. improvement in self-management of medical/somatic condition(s)
Instruments	Addiction Severity Index (Medical Status) (PD) ¹ California Quality of Life (CA-QOL) (PD) ² Medical Outcomes Study Short Form-12 (SF-12) (Pr) ³ Medical Outcomes Study Short Form-36 (SF-36) (Pr) ⁴ Multnomah (MCAS1) (PD) ⁵ Ohio Mental Health Consumer Outcomes System, Adult Consumer Form A, Part 2 and Form B Part 2 (OH) (PD) ⁶ Rand General Health Scale (PD) ^{7,8,9} Treatment Outcome Package (MA) (Pr) ¹⁰ Also see Domain 10, Recovery: self care, ability to ensure own safety
Notes	^a Where a medical condition interferes with daily functioning or co-exists with a mental condition, and where a mental condition interferes with general health status, has mental health treatment contributed to fostering the person-level conditions that allow for improvement in or contributed to improvement in the medical condition? ^b Defined as diabetes, heart disease, hypertension, arthritis, asthma, other (specify) ^c Defined as physical health, dental health ^d Effective treatment and management of general health conditions has a significant impact on mental health and wellbeing.

Domain	2. Self Care: Alcohol and Substance Use/Abuse^{a,b}
Data Elements /Constructs	2.1. decrease in substance use 2.2. improvement in self-management of substance use
Instruments	Addiction Severity Index (PD) (Drug/Alcohol Status) Alcohol Use Scale (AUS) (PD) ^{11,12,13} AUDIT (PD) ¹⁴ CAGE (PD) ^{15 c} CRAFT (Pr) ¹⁶ Drug Use Scale (DUS) (PD) ^{11,12,13} GAIN (Pr) ¹⁷ Multnomah (MCAS 16) (PD) POSIT (Pr) ¹⁸ Teen version of ASI [C] (PD) Treatment Outcome Package (MA) (Pr) [C] TWEAK (for teens) [C] (PD) ¹⁹ See also Domain 10, Recovery: self care
Notes	^a Where a substance use condition interferes with daily functioning or co-exists with a mental condition, and where a mental condition contributes to substance use, has mental health treatment contributed to fostering the person-level conditions that allow for improvement in or contributed to improvement in substance use? ^b Note: By separating out substance use as a domain for measurement, the group did not intend to imply that treatment of mental health and substance use conditions should be separated. Whether to keep the two co-morbidity domains separate should be re-addressed. Other addictions (e.g., gambling) need to be addressed. ^c This tool is useful for screening for alcohol abuse, but less useful for evaluating treatment outcome

Domain	3. Psychological Symptoms^a
Data Elements /Constructs	3.1. reduction in or absence of symptoms 3.2. reduction in distress around symptoms ^b
Instruments^c	Addiction Severity Index (PD) (Psychiatric Status) ¹ BASIS-32 (Pr) ²⁰ Blessed Dementia Scale (PD) ^{21 c} Brief Psychiatric Rating Scale (PD) ²² Brief Psychiatric Rating Scale -C (PD) [C] CBCL [C] (Pr) ²³ Child and Adolescent Functional Assessment Scale (CAFAS) [C] (Pr) ²⁴ Geriatric Depression Scale (PD) ²⁵ MHSIP Symptom Distress Scale (PD) ²⁶ Mini-Mental State Examination (MMSE) (Pr) ^{27 d} Multnomah (PD) (MCAS 2,3,4,5,17) Ohio Mental Health Consumer Outcomes System, Adult Consumer, Form A, Part 3 and Form B, Part 3 (OH) (PD) Ohio Youth Problem, Functioning, and Satisfaction Scales, Parent Rating, Problem Severity Scale (OH) (Pr) [C,P] Ohio Youth Problem, Functioning, and Satisfaction Scales, Worker Rating, Problem Severity Scale (OH) (Pr) [C,T] Ohio Youth Problem, Functioning, and Satisfaction Scales, Youth Rating, Problem Severity Scale (OH) (Pr) [C] Patient Health Questionnaire (PHQ) (Pr) ^{28,29} Patient Health Questionnaire--Nine Symptom Checklist (PHQ-9) (Pr) Patient Health Questionnaire-OA (Older Adults) (Pr)

Domain	3. Psychological Symptoms^a
	<p>Positive and Negative Syndrome Scale (PANSS) (PD)^{30,31,32}</p> <p>Symptom Checklist-10-R (PD)³³</p> <p>Symptom Checklist-90-R (MA) (Pr)³⁴</p> <p>Treatment Outcome Package (MA) (Pr)</p> <p>Pediatric Symptom Checklist (PSC) [C,P] (OD)^{35,36}</p> <p>See also Domain 10, Recovery: psychological functioning</p>
Notes	<p>^a Note: in a person-centered approach, the group recommends measuring symptoms rather than hospitalization or out-of-home placement since these are only crude measures of functioning and depend on local circumstances.</p> <p>^b For example, person has symptoms but is able to live effectively with them; has developed strategies to cope with symptoms; is able to recognize he/she is becoming symptomatic; is able to respond to becoming symptomatic.</p> <p>^c There are several condition-specific instruments available but not included here. Examples include the Zung Depression Inventory, Beck Depression Inventory (BDI), Center for Epidemiological Studies-Depression Scale (CES-D), Beck Anxiety Scale, Hamilton Anxiety Scale, and Hamilton Depression Scale.</p> <p>^d Both the Blessed and Mini-Mental State Examination are used to screen for dementia. Scores may improve with treatment of pseudoementia of depression, but particularly the MMSE is not particularly sensitive.</p>

Domain	4. Behavior and Functioning^a
Data Elements /Constructs	<p>4.1. improvement in activities of daily living (ADLs) and instrumental activities of daily living (IADLs)</p> <p>4.2. engagement in activities that provide a sense of meaning and purpose in life</p> <p>4.3. improved functioning in developmentally appropriate and/or chosen, meaningful and/or productive activities^b</p>
Instruments	<p>Addiction Severity Index (Employment/Support Status) (PD)</p> <p>California Quality of Life (CA-QOL) (PD)</p> <p>Medical Outcomes Study Short Form-12 (SF-12) (Pr)</p> <p>Medical Outcomes Study Short Form-36 (SF-36) (MA) (Pr)</p> <p>Multnomah (MCAS 6,7) (PD)</p> <p>Ohio Mental Health Consumer Outcomes System, Adult Consumer Form A, Part 1 and Form B Part 1 (OH) (PD)</p> <p>Ohio Mental Health Consumer Outcomes System, Provider Form A (OH) (PD)</p> <p>Ohio Youth Problem, Functioning, and Satisfaction Scales, Parent Rating, Functioning Scale (OH) [C,P] (Pr)</p> <p>Ohio Youth Problem, Functioning, and Satisfaction Scales, Worker Rating, Functioning Scale (OH) [C,T] (Pr)</p> <p>Ohio Youth Problem, Functioning, and Satisfaction Scales, Youth Rating, Functioning Scale (OH) [C] (Pr)</p> <p>Sickness Impact Profile (Pr)³⁷</p> <p>Treatment Outcome Package (MA) (Pr)</p> <p>Behavior Assessment System for Children, Second Edition (BASC-2) (Pr) [C,T,P]³⁸</p> <p>The Strengths and Difficulties Questionnaire (PD) [C,P,T]^{39,40}</p> <p>Physical Self-Maintenance Scale (PD)⁴¹</p>

Domain	4. Behavior and Functioning^a
	<p>Medical Expenditure Panel Survey (MEPS), Health Status Section (ADLs and IADLs) (PD)⁴²</p> <p>Functional Impairment Measure (FIM) (PD)^{43,44}</p> <p>Overt Aggression Scale for people with dementia⁴⁵</p> <p>Overt Behavior Scale for people with Traumatic Brain Injury⁴⁶</p> <p>See also Domain 10, Recovery: meaning and purpose, psychological functioning</p>
Notes	<p>^a This domain focuses on skills and capacity to perform activities and roles; social connectedness, quality of relationships, etc. are measured elsewhere</p> <p>^b For example, work, school, parenting, volunteering, etc. For children, indicators of improved academic/school functioning include overall and subject-specific academic performance, school avoidance/attendance, in- and out of school suspension(s), expulsions, and performance-related behaviors such as carelessness, cheating, disorganization, forgetfulness, distractibility, concentration.</p>

Domain	5. Relationships and Social Support
Data Elements /Constructs	<p>5.1. improved ability to form and sustain relationships characterized by trust, respect, mutuality, reciprocity</p> <p>5.2. improved ability to recognize, seek help for, and address abusive relationships ^a</p> <p>5.3. improved relationships with natural networks including family, peers ^b</p> <p>5.4. improved sense of belonging to the larger community</p> <p>5.5. improved participation in social, recreational, and civic activities ^c</p> <p>5.6 feels that there is at least one person in his/her life who believes in him/her</p>
Instruments	<p>Addiction Severity Index (PD) (Family/Social Relationships)</p> <p>California Quality of Life (CA-QOL) (PD)</p> <p>Lehman Quality of Life Scale (Pr) ⁴⁷</p> <p>Multnomah (MCAS 9,1011,12) (PD)</p> <p>Ohio Mental Health Consumer Outcomes System, Adult Consumer Form A, Part 1 and Form B Part 1 (OH) (PD)</p> <p>Ohio Mental Health Consumer Outcomes System, Provider Form A (OH) (PD)</p> <p>The Social Network Map (PD) ⁴⁸</p> <p>See also Domain 10, Recovery: ability to ensure own safety, relationships and social support, integration</p>
Notes	<p>^a Related to recovery item 10.12 (ability to ensure own safety)</p> <p>^b Family is interpreted broadly to include biological, chosen, foster, adoptive, etc.</p> <p>^c For example, clubs, sports teams, dating, voting, advocacy</p>

Domain	6. Family Functioning ^a
Data Elements /Constructs	<p>6.1. improvement in functioning as an integrated unit ^b</p> <p>6.2. increase in knowledge and skills to provide support and care as needed ^c</p> <p>6.3 increase in knowledge and skills to obtain support and care as needed ^c</p> <p>6.4 reduction in level of distress around family relationships</p>
Instruments	<p>Addiction Severity Index (Family/Social Relationships) (PD)</p> <p>Caregiver strain (PD) ⁴⁹</p> <p>California Quality of Life (CA-QOL) (PD)</p> <p>Child and Adolescent Needs and Strengths Information Integration Tool (CANS-MH) [C] (PD) ⁵⁰</p> <p>Ohio Mental Health Consumer Outcomes System, Adult Consumer Form A, Part 1 and Form B Part 1 (OH) (PD)</p> <p>See also Domain 10, Recovery: greater knowledge about treatment/condition</p>
Notes	<p>^a This domain applies to families that include both child and adult consumers. It recognizes the range of relationships that constitutes “family” both in terms of degree of involvement and type of family, e.g. biological, chosen, foster, adoptive, etc. This domain also includes paid and unpaid caregivers in community, residential and long-term care settings.</p> <p>^b For example, improved resilience, sense of competence, stability; reduction in caregiver strain</p> <p>^c This includes ability to act as treatment partners and ability to obtain information.</p>

Domain	7. Adverse Events and Negative Outcomes
Data Elements /Constructs	<p>7.1. reduction in or no negative contacts with the adult or juvenile criminal justice systems ^a</p> <p>7.2. decrease in risk behavior, e.g., harm to self or others ^b</p> <p>7.3. moved out of homelessness</p> <p>7.4. decrease in adverse medication outcomes ^c</p> <p>7.5. decrease in adverse medical outcomes ^d</p> <p>7.6 decrease in risk for falls in elderly persons</p>
Instruments	<p>Adult Needs and Strengths Assessment (ANSA) (PD) ⁵¹</p> <p>Addiction Severity Index (Legal Status) (PD)</p> <p>California Quality of Life (CA-QOL) (PD)</p> <p>Ohio Mental Health Consumer Outcomes System, Provider Form A (OH) (PD)</p> <p>See Domain 3 for specific psychological symptom measures</p> <p>See also Domain 10, Recovery: ability to ensure own safety</p>
Notes	<p>^a Includes arrests, detention, time in jail or prison</p> <p>^b Related to recovery item 10.12 (ability to ensure own safety).</p> <p>^c Analysis will need to determine whether the adverse outcomes are related to consumer or provider actions.</p> <p>^d These data can be obtained from administrative databases.</p>

Domain	8. Engagement in Treatment ^a
Data Elements /Constructs	8.1. improved engagement in/adherence to treatment ^a
Instruments	Multnomah (MCAS 14,15) (PD) Stages of Change Readiness and Treatment Eagerness Scale (SOCRATES) (PD) ⁵² See also Domain 10, Recovery: empowerment in treatment
Notes	^a Treatment is defined broadly to include traditional, peer, and alternative and complementary interventions. ^b Improvement is the result of improved understanding of condition and engagement in treatment planning. For example, the person has greater knowledge and awareness of the full array of treatment options; has improved therapeutic alliance; has improved use of support system; enters into treatment; actively engages in and remains in treatment as long as necessary; shows readiness to change; adheres to recommendations regarding treatment (type, frequency, duration); adheres to medication; is an informed participant in the treatment process and treatment decision-making. This also involves improved ability to talk to authority figures, to advocate for oneself (adults and children) and/or for a child and/or a family, and to refuse treatment. The workgroup notes that this is an intermediate outcome that influences other outcomes.

Domain	9. Quality of Life
Data Elements /Constructs	<p>9.1. improved ability to meet basic needs for nutritious food, safe and affordable housing ^a, physical/personal safety, healthcare, transportation</p> <p>9.2. improved ability to maintain a sustainable source of income</p> <p>9.3. improved opportunities for spiritual and leisure activities</p>
Instruments	<p>California Quality of Life (CA-QOL) (PD)</p> <p>Medical Outcomes Study Short Form-36 (SF-36) (MA) (Pr)</p> <p>Multnomah (PD)</p> <p>Ohio Mental Health Consumer Outcomes System, Adult Consumer, Form A, Part 1, 2, 5 (OH) (PD)</p> <p>Ohio Mental Health Consumer Outcomes System, Provider Form A (OH) (PD)</p> <p>Ohio Youth Problem, Functioning, and Satisfaction Scales, Parent Rating (OH) [C,P] (Pr)</p> <p>Ohio Youth Problem, Functioning, and Satisfaction Scales, Youth Rating (OH) [C] (Pr)</p> <p>See also Domain 10, Recovery: quality of life</p>
Notes	^a Living situation is stable, permanent (for children), safe, desired by the consumer

Domain	10. Recovery ^{a,b}
Data Elements /Constructs	<p>10.1. Feels hopeful about the future (Hope)</p> <p>10.2 Feels empowered (Agency)</p> <p>10.3. Feels able to determine the direction of his/her life (Self-Determination)</p> <p>10.4 Shows increased motivation to change (Awareness and Potentiality)</p> <p>10.5 Acceptance and integration of one’s illness-related experiences (Re-Authoring)</p> <p>10.6 Acceptance and integration of one’s culture (Re-Authoring)</p> <p>10.7 Improvement in self-esteem, sense of self, self-respect, dignity, self-efficacy (perceived and actual) (Well-being)</p> <p>10.8 Has created a life that is broadened rather than limited by the experience of mental illness (Thriving)</p>
Data Elements covered in other domains	<p>For empowerment in treatment, see 8.1</p> <p>For meaning and purpose, see 4.2, 4.3</p> <p>For self care, see 1.1, 1.2, 1.3, 2.1, 2.2</p> <p>For psychological functioning, see 3.1, 3.2, 4.1, 4.2, 4.3</p> <p>For greater knowledge about treatment/condition (Knowledge), see 6.2</p> <p>For ability to ensure own safety, see 1.2, 5.2, 7.2</p> <p>For relationships and social support, see 5.1, 5.2, 5.3, 5.4, 5.5</p> <p>For quality of life, see 9.1, 9.2, 9.3</p> <p>For integration, see 5.4</p>
Instruments ^c	<p>Recovery Measures Compendium, Second Edition (Pr)^{53,54,55}</p> <p>Consumer CROS 3.0 (Pr)⁵⁶</p> <p>Crisis Hostel Healing Scale (PD)</p>

Domain	10. Recovery ^{a,b}
	<p>Mental Health Recovery Measure (MHRM) (PD – with author citation and contact retained on the form)</p> <p>Multnomah (MCAS 8,13) (PD)</p> <p>Ohio Mental Health Consumer Outcomes System, Adult Consumer Form A, Parts 1, 4 (OH) (PD)</p> <p>Recovery Assessment Scale (PD) ⁵⁷</p> <p>Recovery Oriented Survey Instrument (ROSI) (PD) ⁵⁸</p> <p>Recovery Self-Assessment (RSA) (PD) ⁵⁹</p> <p>Recovery-Enhancing Environment Measure (REE) (Pr) ⁶⁰</p> <p>Herth Hope Index ⁶¹</p> <p>The Making Decisions Empowerment Scale (PD)⁶²</p>
Notes	<p>^a Recovery consists of a number of discrete but related elements as described by Onken and colleagues ⁶³</p> <p>^b Many of the data elements listed above are represented in other domains, as specified.</p> <p>^c Recovery instruments under development include the Recovery Measurement Tool (RMT) and the Peer Outcomes Protocol Questionnaire (Campbell, Cook, Jonikas, Einspahr)</p>

Appendix 1. Data Standards for Measuring and Reporting Outcomes

Domain	Data Element	Definitions	Instruments	Uses
Self Care: General Health and Co-morbidity			Addiction Severity Index (Medical Status) (PD) ¹ California Quality of Life (CA-QOL) (PD) ² Medical Outcomes Study Short Form-12 (SF-12) (Pr) ³ Medical Outcomes Study Short Form-36 (SF-36) (Pr) ⁴ Multnomah (MCAS1) (PD) ⁵ Ohio Mental Health Consumer Outcomes System, Adult Consumer Form A, Part 2 and Form B Part 2 (OH) (PD) ⁶ Rand General Health Scale (PD) ^{7,8,9} Treatment Outcome Package (MA) (Pr) ¹⁰	These data elements are applicable to persons with a medical condition that interferes with daily functioning or co-exists with a mental condition and persons whose mental condition interferes with their general health status. The data elements help determine whether mental health treatment has contributed to fostering the conditions that allow for improvement in or has contributed to improvement in the medical condition.
	Improvement in co-morbid medical/somatic condition(s)	Medical conditions include diabetes, heart disease, hypertension, arthritis, asthma, and other specified conditions		
	Improvement in general health	Includes dental health		
	Improvement in self-management of medical/somatic condition(s)			
Self Care:			Addiction Severity Index (PD)	These data elements are applicable to

Domain	Data Element	Definitions	Instruments	Uses
Alcohol and Substance Use/Abuse			(Drug/Alcohol Status) Alcohol Use Scale (AUS) (PD) ^{11,12,13} AUDIT (PD) ¹⁴ CAGE (PD) ¹⁵ CRAFT (Pr) ¹⁶ Drug Use Scale (DUS) (PD) ^{11,12,13} GAIN (Pr) ¹⁷ Multnomah (MCAS 16) (PD) POSIT (Pr) ¹⁸ Teen version of ASI [C] (PD) Treatment Outcome Package (MA) [C] TWEAK (for teens) [C] (PD) ¹⁹	persons with a substance use condition that interferes with daily functioning or co-exists with a mental condition and persons whose mental condition contributes to substance use. The data are used to determine whether mental health treatment has contributed to fostering the conditions that allow for improvement in or has contributed to improvement in substance use.
	Decrease in substance use			
	Improvement in self-management of substance use			
Psychological Symptoms			There are several condition-specific instruments available but not included here. Addiction Severity Index (PD) (Psychiatric Status)	

Domain	Data Element	Definitions	Instruments	Uses
			<p>BASIS-32 (Pr) ²⁰</p> <p>Blessed Dementia Scale (PD) ²¹</p> <p>Brief Psychiatric Rating Scale (PD) ²²</p> <p>Brief Psychiatric Rating Scale -C (PD) [C]</p> <p>CBCL [C] (Pr) ²³</p> <p>Child and Adolescent Functional Assessment Scale (CAFAS) [C] (Pr) ²⁴</p> <p>Geriatric Depression Scale (PD) ²⁵</p> <p>MHSIP Symptom Distress Scale (PD) ²⁶</p> <p>Mini-Mental State Examination (MMSE) (Pr) ²⁷</p> <p>Multnomah (PD) (MCAS 2,3,4,5,17)</p> <p>Ohio Mental Health Consumer Outcomes System, Adult Consumer, Form A, Part 3 and Form B, Part 3(OH) (PD)</p> <p>Ohio Youth Problem, Functioning, and Satisfaction Scales, Parent Rating, Problem Severity Scale (OH) [C,P] (Pr)</p> <p>Ohio Youth Problem, Functioning, and Satisfaction Scales, Worker Rating, Problem Severity Scale (OH) [C,T] (Pr)</p>	

Domain	Data Element	Definitions	Instruments	Uses
			<p>Ohio Youth Problem, Functioning, and Satisfaction Scales, Youth Rating, Problem Severity Scale (OH) [C] (Pr)</p> <p>Patient Health Questionnaire (PHQ) (Pr) 28,29</p> <p>Patient Health Questionnaire--Nine Symptom Checklist (PHQ-9) (Pr)</p> <p>Patient Health Questionnaire for Older Adults (PHQ-OA) (Pr)</p> <p>Positive and Negative Syndrome Scale (PANSS)^{30,31,32}</p> <p>Symptom Checklist-10-R (PD)³³</p> <p>Symptom Checklist-90-R (MA) (Pr)³⁴</p> <p>Treatment Outcome Package (MA) (Pr)</p>	
	Reduction in or absence of symptoms			
	Reduction in distress around symptoms	For example, person has symptoms but is able to live effectively with them; has developed strategies to cope with symptoms; is able to recognize he/she is becoming symptomatic; is able to respond to becoming symptomatic.		
Behavior and				These data elements are used to

Domain	Data Element	Definitions	Instruments	Uses
Functioning				measure skills and capacity to perform activities and roles; social connectedness, quality of relationships, etc. are measured elsewhere.
	Improvement in activities of daily living and instrumental activities of daily living		Addiction Severity Index (Employment/Support Status) (PD) California Quality of Life (CA-QOL) (PD) Medical Outcomes Study Short Form-12 (SF-12) (Pr) Medical Outcomes Study Short Form-36 (SF-36) (MA) (Pr) Multnomah (MCAS 6,7) (PD) Ohio Mental Health Consumer Outcomes System, Adult Consumer Form A, Part 1 and Form B Part 1 (OH) (PD) Ohio Mental Health Consumer Outcomes System, Provider Form A (OH) (PD) Ohio Youth Problem, Functioning, and Satisfaction Scales, Parent Rating, Functioning Scale (OH) [C,P] (Pr) Ohio Youth Problem, Functioning, and Satisfaction Scales, Worker Rating, Functioning Scale (OH) [C,T] (Pr) Ohio Youth Problem, Functioning, and	

Domain	Data Element	Definitions	Instruments	Uses
			<p>Satisfaction Scales, Youth Rating, Functioning Scale (OH) [C] (Pr)</p> <p>Sickness Impact Profile (Pr) ³⁵</p> <p>Treatment Outcome Package (MA) (Pr)</p> <p>The Strengths and Difficulties Questionnaire (PD) [C,P,T] ^{36,37}</p> <p>Physical Self-Maintenance Scale (PD) ³⁸</p> <p>Medical Expenditure Panel Survey (MEPS), Health Status Section (ADLs and IADLs) (PD) ³⁹</p> <p>Functional Impairment Measure (FIM) (PD) ^{40,41}</p> <p>Overt Aggression Scale for people with dementia ⁴²</p> <p>Overt Behavior Scale for people with Traumatic Brain Injury ⁴³</p>	
	Engagement in activities that provide a sense of meaning and purpose in life			
	Improved functioning in developmentally appropriate and/or	For example, work, school, parenting, volunteering, etc		

Domain	Data Element	Definitions	Instruments	Uses
	chosen, meaningful and/or productive activities			
Relationships and Social Support			Addiction Severity Index (PD) (Family/Social Relationships) California Quality of Life (CA-QOL) (PD) Lehman Quality of Life Scale (Pr) ⁴⁴ Multnomah (MCAS 9,1011,12) (PD) Ohio Mental Health Consumer Outcomes System, Adult Consumer Form A, Part 1 and Form B Part 1 (OH) (PD) Ohio Mental Health Consumer Outcomes System, Provider Form A (OH) (PD) The Social Network Map (PD) ⁴⁵	
	Improved ability to form and sustain relationships characterized by trust, respect, mutuality, reciprocity			
	Improved ability to recognize, seek help for, and address abusive relationships			
	Improved relationships with	Family is interpreted broadly to include		

Domain	Data Element	Definitions	Instruments	Uses
	natural networks including family, peers	biological, chosen, foster, adoptive, etc.		
	Improved sense of belonging to the larger community			
	Improved participation in social, recreational, and civic activities	For example, clubs, sports teams, dating, voting, advocacy		
	Feels that there is at least one person in his/her life who believes in him/her			
Family Functioning		This domain applies to families that include both child and adult consumers. It recognizes the range of relationships that constitutes “family” both in terms of degree of involvement and type of family, e.g. biological, chosen, foster, adoptive, etc.	Addiction Severity Index (Family/Social Relationships) (PD) Caregiver strain (PD) ⁴⁶ California Quality of Life (CA-QOL) (PD) Child and Adolescent Needs and Strengths Information Integration Tool (CANS-MH) [C] (PD) ⁴⁷ Ohio Mental Health Consumer Outcomes System, Adult Consumer Form A, Part 1 and Form B Part 1 (OH) (PD)	
	Improvement in functioning as an integrated unit	For example, improved resilience, sense of competence, stability; reduction in caregiver strain		
	Increase in	This includes ability to act		

Domain	Data Element	Definitions	Instruments	Uses
	knowledge and skills to provide support and care as needed	as treatment partners and ability to obtain information.		
	Increase in knowledge and skills to obtain support and care as needed	This includes ability to act as treatment partners and ability to obtain information.		
	Reduction in level of distress around family relationships			
Adverse Events and Negative Outcomes			<p>Adult Needs and Strengths Assessment (ANSA) (PD) ⁴⁸</p> <p>Addiction Severity Index (Legal Status) (PD)</p> <p>California Quality of Life (CA-QOL) (PD)</p> <p>Ohio Mental Health Consumer Outcomes System, Provider Form A (OH) (PD)</p>	
	Reduction in or no contacts with the adult or juvenile criminal justice systems	Includes arrests, detention, time in jail or prison		
	Decrease in risk behavior, e.g., harm to self or others			
	Moved out of homelessness			

Domain	Data Element	Definitions	Instruments	Uses
	Decrease in adverse medication outcomes	Includes adverse outcomes related to both consumer and provider actions		
	Decrease in adverse medical outcomes			
Engagement in Treatment			Multnomah (MCAS 14,15) (PD) Stages of Change Readiness and Treatment Eagerness Scale (SOCRATES) (PD) ⁴⁹	This is an intermediate outcome that influences other outcomes.
	Improved engagement in/adherence to treatment	Improvement is the result of improved understanding of condition and engagement in treatment planning. For example, the person has greater knowledge and awareness of the full array of treatment options; has improved therapeutic alliance; has improved use of support system; enters into treatment; actively engages in and remains in treatment as long as necessary; shows readiness to change; adheres to recommendations regarding treatment (type, frequency, duration); adheres to medication; is an informed participant in the treatment process and treatment decision-making.		

Domain	Data Element	Definitions	Instruments	Uses
		This also involves improved ability to talk to authority figures, to advocate for oneself (adults and children) and/or for a child and/or a family, and to refuse treatment.		
Quality of Life			<p>California Quality of Life (CA-QOL) (PD)</p> <p>Medical Outcomes Study Short Form-36 (SF-36) (MA) (Pr)</p> <p>Multnomah (PD)</p> <p>Ohio Mental Health Consumer Outcomes System, Adult Consumer, Form A, Part 1, 2, 5 (OH) (PD)</p> <p>Ohio Mental Health Consumer Outcomes System, Provider Form A (OH) (PD)</p> <p>Ohio Youth Problem, Functioning, and Satisfaction Scales, Parent Rating (OH) [C,P] (Pr)</p> <p>Ohio Youth Problem, Functioning, and Satisfaction Scales, Youth Rating (OH) [C] (Pr)</p>	
	Improved ability to meet basic needs for nutritious food, safe and affordable housing,	Improvement in living situation refers to housing that is stable, permanent (for children), safe, and desired by the consumer		

Domain	Data Element	Definitions	Instruments	Uses
	physical/personal safety, healthcare, transportation			
	Improved ability to maintain a sustainable source of income			
	Improved opportunities for spiritual and leisure activities			
Recovery		Recovery consists of a number of discrete but related elements as described in Exhibit 1 ⁵³	Recovery Measures Compendium, Second Edition (Pr) ^{50,51,52} Consumer CROS 3.0 (Pr) ⁵³ Crisis Hostel Healing Scale (PD) Mental Health Recovery Measure (MHRM) (PD – with author citation and contact retained on the form) Multnomah (MCAS 8,13) (PD) Ohio Mental Health Consumer Outcomes System, Adult Consumer Form A, Parts 1, 4 (OH) (PD) Recovery Assessment Scale (PD) ⁵⁴ Recovery Oriented Survey Instrument (ROSI) (PD) ⁵⁵ Recovery Self-Assessment (RSA) (PD) ⁵⁶	

Domain	Data Element	Definitions	Instruments	Uses
			Recovery-Enhancing Environment Measure (REE) (Pr) ⁵⁷ Herth Hope Index ⁵⁸ The Making Decisions Empowerment Scale (PD) ⁵⁹ Recovery instruments under development include the Recovery Measurement Tool (RMT) and the Peer Outcomes Protocol Questionnaire (Campbell, Cook, Jonikas, Einspahr)	
	Feels hopeful about the future (Hope)			
	Feels empowered (Agency)			
	Feels able to determine the direction of his/her life (Self-Determination)			
	Shows increased motivation to change (Awareness and Potentiality)			
	Acceptance and integration of one's illness-related experiences (Re-Authoring)			
	Acceptance and			

Domain	Data Element	Definitions	Instruments	Uses
	integration of one's culture (Re-Authoring)			
	Improvement in perceived and actual self-esteem, sense of self, self-respect, dignity, self-efficacy (Well-being)			
	Has created a life that is broadened rather than limited by the experience of mental illness (Thriving)			
	Empowerment in treatment	See Domain: Engagement in Treatment		
	Meaning and purpose	See Domain: Behavior and Functioning		
	Self care	See Domain: Self Care: General Health and Comorbidity and Domain: Self Care: Alcohol and Substance Use/Abuse		
	Psychological functioning	See Psychological Symptoms, Behavior and Functioning		
	Greater knowledge about treatment/condition (Knowledge)	See Domain: Family Functioning		
	Ability to ensure own safety	See Domain: Self Care: General Health and		

Domain	Data Element	Definitions	Instruments	Uses
		Comorbidity, Relationships and Domain: Social Support, Adverse Events and Negative Outcomes		
	Relationships and social support	See Domain: Relationships and Social Support		
	Quality of life	See Domain: Quality of Life		
	Integration	See Domain: Relationships and Social Support		

Appendix 2. Glossary of Terms

Elements of Recovery (extracted from Onken et al., 2004⁵³)	
Person-centered elements of recovery	
Hope	Hope is identified as central to recovery and is accomplished by the individual through interactions with others in the environment, whether those interactions foster or obstruct the establishment of hopefulness. It is often the expectation of better things—reduction of symptoms, better physical surroundings, or emotional support—that propels a person toward an improved life situation and incites the desire to take steps in that direction.
Sense of Agency	Recovery is often characterized as rooted in a sense of agency (i.e., goal-directed determination) and most often in self-agency. Individual is competent and aware of own ability to face the challenges posed by the psychiatric disability, treatment, and the stigma imposed by the wider society.
Self-Determination	Self-determination plays prominently in the recovery process, as an individual must have the freedom to design his or her own life path to engage in the work of recovery. Self-determination includes the ability to make choices and to understand the consequences of choices and their impact on others, and can be propelled by the availability of personal choice within treatment. It is associated with progress toward independence from the publicly funded system and with resilience and strength.
Meaning and Purpose	Recovery is partly dependent upon the ability of the individual to find and pursue meaning and purpose in his or her life “and this ability is derived through the interaction of the individual’s internal drive within an environment that offers valued supports and opportunities”.
Awareness and Potentiality	Individuals in the recovery process must develop an awareness that positive change is possible and involves the notion that one is capable of engaging in change. It is also related to readiness to change and hope.
Re-authoring elements of recovery	
Re-Authoring	The re-authoring process is the task of recasting the life experience in a manner through which the individual is able to reclaim a positive self-identity that incorporates but does not center on the illness and associated traumas. It is related to acceptance and integration. Re-Authoring

Elements of Recovery (extracted from Onken et al., 2004⁵³)	
	begins with the development of coping skills and develops as the individual engages in the often-painful healing process, accomplishes mental, physical and spiritual wellness and is able to thrive due in part to the experience of illness that broadened the life experience. The elements of the Re-Authoring Process are interlinked, with differences between them being largely a matter of degree (i.e., an individual may consistently incorporate coping techniques and modulate the effects of the illness [wellness] or may be in the beginning stages of identifying coping skills [coping]).
Coping	Coping is the beginning of the Re-Authoring Process and hinges on the individual's ability to identify unique techniques that enable him or her to weather the illness.
Healing	The healing process involves overcoming the harm incurred through an individual's experience with the illness as well as with the associated stigma and discrimination. It is associated with acceptance and integration.
Wellness	Wellness encompasses the development and use of coping skills to promote health and navigate the challenges presented by the psychiatric disability and life stressors. It involves the ability to care for oneself in a holistic way - mental, physical and spiritual wellness.
Thriving	Thriving is a process in which individuals' experiences of dealing with traumatic life events lead them to become better off than they were beforehand. When thriving, individuals rebuild their lives through the Re-Authoring Process, creating lives that are broadened rather than limited by the experience of mental illness.
Exchange-centered elements of recovery	
Social Functioning	The elements of Social Functioning and Social Roles, Power, and Choice Among Meaningful Options are realms in which individuals are able to engage as a result of the Re-Authoring Process and are also dependent on an exchange with the wider community.
Social Roles	Recovery involves active involvement in social roles, either by regaining roles that were lost or through the creation of new social roles. Peer support can play an integral role in promoting positive social functioning.
Power	Recovery is political as well as personal- to recover fosters expressions of power and collective social action. Individuals tap into and expand on their own power often through the referent power of common community with

Elements of Recovery (extracted from Onken et al., 2004⁵³)	
	like individuals, shaping their life experience as well as the wider community.
Choice Among Meaningful Options	Recovery is not possible without meaningful options from which to choose (treatment options, jobs, education, living arrangements). Opportunities need to be present to build choice making skills and to take risks.
Community-centered elements of recovery	
Social connectedness/relationships	The elements of Social Connectedness/Relationships, Social Circumstances/Opportunities and Integration rely on opportunities within the community. Human connection plays a large role in the healing process and recovery. The process of recovery is moved forward through interaction with others in supportive relationships.
Social circumstances/opportunities	Relevant instrumental (material) supports and social opportunities must be available for person-based capacity to develop. Recovery is promoted through the provision of opportunities within the community, involving basic needs, meaningful activities, valued roles as well as trusting relationships. None of the elements of recovery are possible in a vacuum of valued opportunities.
Integration	The ability to live among (and interact with) others—mutual positive interdependence—is a hallmark of community and an underpinning of the recovery process. Integration involves both the incorporation of the illness into the self-concept as well as the individual into the wider community.

References For Recommendations for Domains, Data Elements, and Instruments

¹ McLellan AT, Kushner H, Metzger D, Peters R, Smith I, Grissom G, Pettinati H, Argeriou M. The fifth edition of the Addiction Severity Index.. *Journal of Substance Abuse Treatment* 1992; 9:199-213.

² Purvis K, Higgins J. Pilot to evaluate alternative quality of life assessment instruments. Research and Performance Outcome Development Unit, California State Department of Mental Health, October 1998.

³ Salyers MP, Bosworth HB, Swanson JW, Lamb-Pagone J, Osher FC. Reliability and validity of the SF-12 health survey among people with severe mental illness. *Medical Care* 2000;38:1141-1150.

⁴ Hemingway H, Stafford M, Stansfeld S, Shipley M, Marmot M. Is the SF-36 a valid measure of change in population health? Results from the Whitehall II study. *British Medical Journal* 1997; 315:1273-1279.

⁵ Hendryx M , Dyck DG, McBride D, Whitbeck J. A test of the reliability and validity of the Multnomah Community Ability Scale. *Community Mental Health Journal* 2001;37:157-168.

⁶ Brower LA, The Ohio mental health consumer outcomes system: reflections on a major policy initiative in the US. *Clinical Psychology & Psychotherapy* 2003; 10: 400-406

⁷ Ware JE, Scales for measuring general health perceptions. *Health Services Research* 1976 1:396-415.

⁸ Ware JE, Karmos AH. Development and validation of scales to measure perceived health and patient role propensity. Vol.2 of a Final Report, NTIS publication No. PB 288-331, Springfield, VA National Technical Information Service, 1976.

⁹ Ware JE, Davies-Avery A, Donald CA. Conceptualization and measurement of health for adults in the health insurance study: Vol 5: General Health Perceptions R-1987/5-HEW, Santa Monica, CA, The Rand Corporation, 1978.

¹⁰ Kraus DR, Seligman DA, Jordan JR. Validation of a behavioral health treatment outcome and assessment tool designed for naturalistic settings: The Treatment Outcome Package. *Journal of Clinical Psychology* 2005;61:315-322.

¹¹ Drake RE. Toolkit for Evaluating Substance Abuse in Persons with Severe Mental Illness. 1995.

¹² Drake RE, Mueser KT, McHugo GJ. In LI Sederer and B Dickey (Eds.) *Outcomes Assessment in Clinical Practice*, 113-116. Baltimore, MD, Williams & Wilkins, 1996.

-
- ¹³ Drake RE, Wallach M. Substance abuse among chronic mentally ill. *Hospital and Community Psychiatry* 1989;40:1041-1046.
- ¹⁴ Babor T, de la Fuente JR, Saunders J, Grant M. AUDIT, the alcohol use disorders identification test: guidelines for use in primary health care. Geneva, World Health Organization, 1989.
- ¹⁵ Chan AW, Pristach EA, Welte JW. Detection by the CAGE of alcoholism or heavy drinking in primary care outpatients and the general population. *Journal of Substance Abuse* 1994;6:123-135.
- ¹⁶ Miller WR, Tonigan JS. Comparison of drug use outcomes for treatment resistant vs. treatment-seeking clients. Center on Alcoholism, Substance Abuse, and Addictions (CASAA), University of New Mexico.
<http://casaa.unm.edu/posters/Comparison%20of%20Drug%20Use%20Outcomes%20for%20Treatment%20Resistant%20vs%20Treatment-Seeking%20Clients.pdf> accessed 11/11/05.
- ¹⁷ <http://www.chestnut.org/LI/gain/index.html#GAIN%20Licensing%20Information> accessed 11/11/05.
- ¹⁸ Santisteban DA, Tejada M, Dominicis C, Szapocznik J. An efficient tool for screening for maladaptive family functioning in adolescent drug abusers: The Problem Oriented Screening Instrument for Teenagers. *American Journal of Drug and Alcohol Abuse* 1999; 25:197-206.
- ¹⁹ Chan AW, Pristach EA, Welte JW, Russell M. Use of the TWEAK test in screening for alcoholism/heavy drinking in three populations. *Alcohol Clinical and Experimental Research* 1993;17:1188-92.
- ²⁰ Eisen SV, Wilcox M, Leff HS, Schaefer E, Culhane MA. Assessing behavioral health outcomes in outpatient programs: reliability and validity of the BASIS-32. *Journal of Behavioral Health Services Research* 1999;26:5-17.
- ²¹ Blessed G, Tomlinson BE, Roth M. Blessed-Roth Dementia Scale (DS). *Psychopharmacology Bulletin* 1988;24:705-708.
- ²² Ventura MA, Green MF, Shaner A, Liberman RP. Training and quality assurance with the brief psychiatric rating scale: "The drift buster". *International Journal of Methods in Psychiatric Research* 1993;3:221-244.
- ²³ <http://www.aseba.org/products/forms.html> accessed 11/14/05
- ²⁴ Hodges K, Wong MM, Latessa M. Use of the Child and Adolescent Functional Assessment Scale (CAFAS) as an outcome measure in clinical settings. *Journal of Behavioral Health Services Research* 1998;3:325-36.

-
- ²⁵ Yesavage JA, Brink TL, Rose TL, Lum O, Huang V, Adey M, Leirer VO. Development and validation of a geriatric depression screening scale: a preliminary report. *Journal of Psychiatric Research* 1982-83;17:37-49.
- ²⁶ MHSIP Consumer Report Card, 1996. <http://www.mhsip.org/reportcard/sympdiss.pdf> accessed 11/14/05.
- ²⁷ Tombaugh TN, McIntyre NJ. The mini-mental state examination: a comprehensive review. *Journal of American Geriatric Society*. 1992;40:922-35.
- ²⁸ Spitzer RL, Kroenke K, Williams JB. Validation and utility of a self-report version of PRIME-MD: the PHQ primary care study. Primary Care Evaluation of Mental Disorders. Patient Health Questionnaire. *JAMA* 1999;282:1737-44.
- ²⁹ Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. *Journal of General Internal Medicine*. 2001;16:606-13.
- ³⁰ Bell M, Milstein R, Beam-Goulet J, Lysaker P, Cicchetti D. The Positive and Negative Syndrome and the Brief Psychiatric Rating Scale: Reliability, comparability, and predictive validity. *Journal of Nervous and Mental Disease* 1992;80:723-728.
- ³¹ Kay SR, Fiszbein A, Opler LA. The positive and negative syndrome scale (PANSS) for schizophrenia. *Schizophrenia Bulletin* 1987;13:261-276.
- ³² Kay SR, Opler LA, Lindenmayer JP. The positive and negative syndrome scale (PANSS): Rationale and standardization. *British Journal of Psychiatry* 1989; 155 (Suppl. 7), 59-65.
- ³³ Rosen C, Dreschler K, Moos R, Finney J, Murphy R, Gusman F. Six and Ten Item Indices of Psychological Distress Based on the Symptom Checklist-90. *Assessment*. 2000; 7:103-111.
- ³⁴ Peveler RC, Fairburn CG. Measurement of neurotic symptoms by self-report questionnaire: validity of the SCL-90R. *Psychology and Medicine* 1990;20:873-9.
- ³⁵ Jellinek MS, Murphy JM, Robinson J, et al. The Pediatric Symptom Checklist: Screening school-age children for psychosocial dysfunction. *J Pediatr* 1988; 12:201-209.
- ³⁶ http://psc.partners.org/psc_order.htm, accessed June 26, 2006.
- ³⁷ Bergner M, Bobbitt RA, Carter WB, Gilson BS. The Sickness Impact Profile: development and final revision of a health status measure. *Med Care* 1981;19:787-805.
- ³⁸ <http://www.pearsonassessments.com/home.htm>, accessed June 26, 2006.
- ³⁹ <http://www.sdqinfo.com>. Accessed July 26, 2006.
- ⁴⁰ <http://www.sdqinfo.com/b7.html>. Accessed July 26, 2006.

-
- ⁴¹ Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. *Gerontologist* 1969; 9:179-86.
- ⁴² Agency for Healthcare Research and Quality. Medical Expenditure Panel Survey (MEPS), Health Status (HE) Section. http://207.188.212.220/mepsweb/survey_comp/hc_survey/1996/HE-131.pdf#xml=http://207.188.212.220/cgi-bin/taxis/webinator/search/pdfhi.txt?query=activities+of+daily+living&pr=MEPSFULLSITE&prox=page&rorder=500&rprox=500&rdfreq=500&rwfreq=500&rlead=500&sufs=0&order=r&cq=&id=44f366821b. Accessed September 8, 2006.
- ⁴³ Keith RA, Granger CV, Hamilton BB, Sherwin FS. The functional independence measure: a new tool for rehabilitation. *Adv Clin Rehabil.* 1987;1:6-18.
- ⁴⁴ Ottenbacher KJ, Hsu Y, Granger CV, Fiedler RC. The reliability of the functional independence measure: a quantitative review. *Arch Phys Med Rehabil.* 1996;77:1226-32.
- ⁴⁵ Yudofsky S, et al. *Am J Psychiatry* 1989;143:35-39.
- ⁴⁶ Kelly G, Todd J, Simpson G, Kremer P, Martin C. The overt behaviour scale (OBS): A tool for measuring challenging behaviours following ABI in community settings. *Brain Injury.* 2006; 20:307-319.
- ⁴⁷ Lehman AF: Measures of quality of life among persons with severe and persistent mental disorders. *Social Psychiatry and Psychiatric Epidemiology* 1996;31:78-88.
- ⁴⁸ Tracy EM, Whittaker JK. The social network map: Assessing social support in clinical social work practice. *Families in Society* 1990;71:461-470.
- ⁴⁹ Brannan AM, Heflinger CA, Bickman L. The Caregiver Strain Questionnaire: Measuring the impact on the family of living with a child with serious emotional disturbance. *Journal of Emotional and Behavioral Disorders* 1997;5:212-222.
- ⁵⁰ Child and Adolescent Needs and Strengths. An Information Integration Tool for Children and Adolescents with Mental Health Challenges. CANS-MH Manual 2003. <http://www.dcf.state.fl.us/mentalhealth/publications/cans4.pdf>. accessed 11/15/05.
- ⁵¹ <http://www.medicine.uiowa.edu/icmh/documents/ANSATool.doc> accessed 11/15/05.
- ⁵² Maisto SA, Conigliaro J, McNeil M, Kraemer K, O'Connor M, Kelley ME. Factor structure of the SOCRATES in a sample of primary care patients. *Addictive Behavior* 1999; 24: 879-92.
- ⁵³ Campbell-Orde T, Chamberlin J, Carpenter J, Leff HS. Measuring the promise: A compendium of recovery measures, Volume II. Cambridge, MA, The Evaluation Center at Human Services Research Institute, 2005. Corresponding author: J. Carpenter

-
- ⁵⁴ Dumont J. In Ralph RO, Kidder K, and Phillips D. (Eds.) Can we measure recovery? A compendium of recovery and recovery-related instruments. Cambridge, MA, Human Services Research Institute, 2000.
- ⁵⁵ Bullock WA. In Campbell-Orde T, Garrett E, and Leff S. (Eds.) Measuring the Promise of Recovery: A compendium of recovery and recovery-related instruments, Part II. Cambridge, MA, The Evaluation Center@HSRI, 2005.
- ⁵⁶ <http://www.crosllc.com/crosdev.htm> accessed 11/15/05.
- ⁵⁷ Corrigan PW, Salzer M, Ralph RO, Sangster Y, Keck L. Examining the factor structure of the recovery assessment scale. *Schizophrenia Bulletin* 2004;30:1035-41.
- ⁵⁸ Onken SJ, Dumont JM, Ridgway P, Dornan DH, Ralph RO. Update on the recovery oriented system indicators (ROSI) measure: Consumer survey and administrative data profile. Proceedings from 2004 Joint National Conference on Mental Health Block Grant and Mental Health Statistics, Washington, D.C., 2004.
- ⁵⁹ <http://www.dmhas.state.ct.us/recovery/RSASummary.pdf>. Accessed 11/16/05.
- ⁶⁰ Ridgway P, Press A, Ratzlaff S, Davidson L, Rapp CA. Report on field testing the Recovery Enhancing Environment Measure. Lawrence, KS, School of Social Welfare, Office of Mental Health Research and Training, 2003.
- ⁶¹ Herth, K. Abbreviated instrument to measure hope: development and psychometric evaluation. *Journal of Advanced Nursing* 1992; 17: 1251-1259.
- ⁶² Rogers ES, Chamberlain J, Ellison ML, Crean T. A consumer-constructed scale to measure empowerment among users of mental health services. *Psychiatric Services* 1997; 48: 1042-1047
- ⁶³ Onken SJ, Craig CM, Ridgeway P, Ralph RO, Cook JA. An analysis of the definitions and elements of recovery: A review of the literature. Pre-conference paper prepared for the National Consensus Conference on Mental Health Recovery and Systems Transformation, Rockville, MD, December, 2004.

References for Data Standards

- ¹ McLellan AT, Kushner H, Metzger D, Peters R, Smith I, Grissom G, Pettinati H, Argeriou M. The fifth edition of the Addiction Severity Index.. *Journal of Substance Abuse Treatment* 1992; 9:199-213.
- ² Purvis K, Higgins J. Pilot to evaluate alternative quality of life assessment instruments. Research and Performance Outcome Development Unit, California State Department of Mental Health, October 1998.

-
- ³ Salyers MP, Bosworth HB, Swanson JW, Lamb-Pagone J, Osher FC. Reliability and validity of the SF-12 health survey among people with severe mental illness. *Medical Care* 2000; 38:1141-1150.
- ⁴ Hemingway H, Stafford M, Stansfeld S, Shipley M, Marmot M. Is the SF-36 a valid measure of change in population health? Results from the Whitehall II study. *British Medical Journal* 1997; 315: 1273 - 1279.
- ⁵ Hendryx M , Dyck DG, McBride D, Whitbeck J. A test of the reliability and validity of the Multnomah Community Ability Scale. *Community Mental Health Journal* 2001; 37: 157-168.
- ⁶ Brower LA, The Ohio mental health consumer outcomes system: reflections on a major policy initiative in the US. *Clinical Psychology & Psychotherapy* 2003; 10: 400-406
- ⁷ Ware JE, Scales for measuring general health perceptions. *Health Services Research* 1976 1:396-415.
- ⁸ Ware JE, Karmos AH. Development and validation of scales to measure perceived health and patient role propensity. Vol.2 of a Final Report, NTIS publication No. PB 288-331, Springfield, VA National Technical Information Service, 1976.
- ⁹ Ware JE, Davies-Avery A, Donald CA. Conceptualization and measurement of health for adults in the health insurance study: Vol 5: General Health Perceptions R-1987/5-HEW, Santa Monica, CA, The Rand Corporation, 1978.
- ¹⁰ Kraus DR, Seligman DA, Jordan JR. Validation of a behavioral health treatment outcome and assessment tool designed for naturalistic settings: The Treatment Outcome Package. *Journal of Clinical Psychology* 2005; 61: 315-322.
- ¹¹ Drake RE. Toolkit for Evaluating Substance Abuse in Persons with Severe Mental Illness. 1995.
- ¹² Drake RE, Mueser KT, McHugo GJ. In LI Sederer and B Dickey (Eds.) *Outcomes Assessment in Clinical Practice*, 113-116. Baltimore, MD, Williams & Wilkins, 1996.
- ¹³ Drake RE, Wallach M. Substance abuse among chronic mentally ill. *Hospital and Community Psychiatry* 1989;40:1041-1046.
- ¹⁴ Babor T, de la Fuente JR, Saunders J, Grant M. AUDIT, the alcohol use disorders identification test: guidelines for use in primary health care. Geneva, World Health Organization, 1989.

-
- ¹⁵ Chan AW, Pristach EA, Welte JW. Detection by the CAGE of alcoholism or heavy drinking in primary care outpatients and the general population. *Journal of Substance Abuse* 1994; 6:123-135.
- ¹⁶ Miller WR, Tonigan JS. Comparison of drug use outcomes for treatment resistant vs. treatment-seeking clients. Center on Alcoholism, Substance Abuse, and Addictions (CASAA), University of New Mexico.
<http://casaa.unm.edu/posters/Comparison%20of%20Drug%20Use%20Outcomes%20for%20Treatment%20Resistant%20vs%20Treatment-Seeking%20Clients.pdf> accessed 11/11/05.
- ¹⁷ <http://www.chestnut.org/LI/gain/index.html#GAIN%20Licensing%20Information> accessed 11/11/05.
- ¹⁸ Santisteban DA, Tejada M, Dominicis C, Szapocznik J. An efficient tool for screening for maladaptive family functioning in adolescent drug abusers: The Problem Oriented Screening Instrument for Teenagers. *American Journal of Drug and Alcohol Abuse* 1999; May.
- ¹⁹ Chan AW, Pristach EA, Welte JW, Russell M. Use of the TWEAK test in screening for alcoholism/heavy drinking in three populations. *Alcohol Clinical and Experimental Research* 1993; 17: 1188-92.
- ²⁰ Eisen SV, Wilcox M, Leff HS, Schaefer E, Culhane MA. Assessing behavioral health outcomes in outpatient programs: reliability and validity of the BASIS-32. *Journal of Behavioral Health Services Research* 1999; 26:5-17.
- ²¹ Blessed G, Tomlinson BE, Roth M. Blessed-Roth Dementia Scale (DS). *Psychopharmacology Bulletin* 1988; 24: 705-708.
- ²² Ventura MA, Green MF, Shaner A, Liberman RP. Training and quality assurance with the brief psychiatric rating scale: "The drift buster". *International Journal of Methods in Psychiatric Research* 1993; 3: 221-244.
- ²³ <http://www.aseba.org/products/forms.html> accessed 11/14/05
- ²⁴ Hodges K, Wong MM, Latessa M. Use of the Child and Adolescent Functional Assessment Scale (CAFAS) as an outcome measure in clinical settings. *Journal of Behavioral Health Services Research* 1998; 3: 325-36.
- ²⁵ Yesavage JA, Brink TL, Rose TL, Lum O, Huang V, Adey M, Leirer VO. Development and validation of a geriatric depression screening scale: a preliminary report. *Journal of Psychiatric Research* 1982-83; 17: 37-49.
- ²⁶ MHSIP Consumer Report Card, 1996. <http://www.mhsip.org/reportcard/sympdiss.pdf> accessed 11/14/05.

-
- ²⁷ Tombaugh TN, McIntyre NJ. The mini-mental state examination: a comprehensive review. *Journal of American Geriatric Society*. 1992; 40: 922-35.
- ²⁸ Spitzer RL, Kroenke K, Williams JB. Validation and utility of a self-report version of PRIME-MD: the PHQ primary care study. *Primary Care Evaluation of Mental Disorders. Patient Health Questionnaire*. *JAMA* 1999;282: 1737-44.
- ²⁹ Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. *Journal of General Internal Medicine*. 2001;16: 606-13.
- ³⁰ Bell M, Milstein R, Beam-Goulet, J, Lysaker P, Cicchetti D. The Positive and Negative Syndrome and the Brief Psychiatric Rating Scale: Reliability, comparability, and predictive validity. *Journal of Nervous and Mental Disease* 1992; 80: 723-728.
- ³¹ Kay SR, Fiszbein A, Opler LA. The positive and negative syndrome scale (PANSS) for schizophrenia. *Schizophrenia Bulletin* 1987; 13: 261-276.
- ³² Kay SR, Opler LA, Lindenmayer JP. The positive and negative syndrome scale (PANSS): Rationale and standardization. *British Journal of Psychiatry*, 155 (Suppl. 7), 59-65. 1989.
- ³³ Rosen C, Dreschler K, Moos R, Finney J, Murphy R, Gusman F. Six and Ten Item Indices of Psychological Distress Based on the Symptom Checklist-90. *Assessment*. 2000; 7: 103-111.
- ³⁴ Peveler RC, Fairburn CG. Measurement of neurotic symptoms by self-report questionnaire: validity of the SCL-90R. *Psychology and Medicine* 1990; 20: 873-9.
- ³⁵ Bergner M, Bobbitt RA, Carter WB, Gilson BS. The Sickness Impact Profile: development and final revision of a health status measure. *Med Care* 1981; 19: 787-805.
- ³⁶ <http://www.sdqinfo.com>. Accessed July 26, 2006.
- ³⁷ <http://www.sdqinfo.com/b7.html>. Accessed July 26, 2006.
- ³⁸ Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. *Gerontologist* 1969; 9:179-86.
- ³⁹ Agency for Healthcare Research and Quality. Medical Expenditure Panel Survey (MEPS), Health Status (HE) Section. http://207.188.212.220/mepsweb/survey_comp/hc_survey/1996/HE-131.pdf#xml=http://207.188.212.220/cgi-bin/taxis/webinator/search/pdfhi.txt?query=activities+of+daily+living&pr=MEPSFULLSITE&prox=page&rorder=500&rprox=500&rdfreq=500&rwfreq=500&rlead=500&sufs=0&order=r&cq=&id=44f366821b. Accessed September 8, 2006.
- ⁴⁰ Keith RA, Granger CV, Hamilton BB, Sherwin FS. The functional independence measure: a new tool for rehabilitation. *Adv Clin Rehabil*. 1987;1:6-18.

-
- ⁴¹ Ottenbacher KJ, Hsu Y, Granger CV, Fiedler RC. The reliability of the functional independence measure: a quantitative review. *Arch Phys Med Rehabil.* 1996;77:1226-32.
- ⁴² Yudofsky S, et al. *Am J Psychiatry* 1989;143:35-39.
- ⁴³ Kelly G, Todd J, Simpson G, Kremer P, Martin C. The overt behaviour scale (OBS): A tool for measuring challenging behaviours following ABI in community settings. *Brain Injury.* 2006; 20:307-319.
- ⁴⁴ Lançon C, Auquier P, Toumi M, Launois R, Llorca P-M, Lehman A, Bebbington P. Evaluation de la qualité de vie des patients schizophrènes : validation de la version courte de la QoLI. *Encephale* 2000; 26 : 11-16.
English version at: <http://www.rees-france.com/Eng/pdf/TUTORIALS/ART-859%20QoL%20I%20Internal%20structure.pdf> accessed 11/14/05.
- ⁴⁵ Tracy EM, Whittaker JK. The social network map: Assessing social support in clinical social work practice. *Families in Society* 1990; 71: 461-470.
- ⁴⁶ Brannan AM, Heflinger CA, Bickman L. The Caregiver Strain Questionnaire: Measuring the impact on the family of living with a child with serious emotional disturbance. *Journal of Emotional and Behavioral Disorders* 1997; 5: 212-222.
- ⁴⁷ Child and Adolescent Needs and Strengths. An Information Integration Tool for Children and Adolescents with Mental Health Challenges. *CANS-MH Manual* 2003.
<http://www.dcf.state.fl.us/mentalhealth/publications/cans4.pdf>. Accessed 11/15/05.
- ⁴⁸ <http://www.medicine.uiowa.edu/icmh/documents/ANSATool.doc> accessed 11/15/05.
- ⁴⁹ Maisto SA, Conigliaro J, McNeil M, Kraemer K, O'Connor M, Kelley ME. Factor structure of the SOCRATES in a sample of primary care patients. *Addictive Behavior* 1999; 24: 879-92.
- ⁵⁰ Campbell-Orde T, Chamberlin J, Carpenter J, Leff HS. *Measuring the promise: A compendium of recovery measures, Volume II.* Cambridge, MA, The Evaluation Center at Human Services Research Institute, 2005. Corresponding author: J. Carpenter
- ⁵¹ Dumont J. In Ralph RO, Kidder K, and Phillips D. (Eds.) *Can we measure recovery? A compendium of recovery and recovery-related instruments.* Cambridge, MA, Human Services Research Institute, 2000.
- ⁵² Bullock WA. In Campbell-Orde T, Garrett E, and Leff S. (Eds.) *Measuring the Promise of Recovery: A compendium of recovery and recovery-related instruments, Part II.* Cambridge, MA, The Evaluation Center@HSRI, 2005.
- ⁵³ <http://www.crosllc.com/crosdev.htm> accessed 11/15/05.

-
- ⁵⁴ Corrigan PW, Salzer M, Ralph RO, Sangster Y, Keck L. Examining the factor structure of the recovery assessment scale. *Schizophrenia Bulletin* 2004; 30:1035-41.
- ⁵⁵ Onken SJ, Dumont JM, Ridgway P, Dornan DH, Ralph RO. Update on the recovery oriented system indicators (ROSI) measure: Consumer survey and administrative data profile. Proceedings from 2004 Joint National Conference on Mental Health Block Grant and Mental Health Statistics, Washington, D.C., 2004.
- ⁵⁶ <http://www.dmhas.state.ct.us/recovery/RSAsummary.pdf>. Accessed 11/16/05.
- ⁵⁷ Ridgway P, Press A, Ratzlaff S, Davidson L, Rapp CA. Report on field testing the Recovery Enhancing Environment Measure. Lawrence, KS, School of Social Welfare, Office of Mental Health Research and Training, 2003.
- ⁵⁸ Herth, K. Abbreviated instrument to measure hope: development and psychometric evaluation. *Journal of Advanced Nursing* 1992; 17: 1251-1259.
- ⁵⁹ Rogers ES, Chamberlain J, Ellison ML, Crean T. A consumer-constructed scale to measure empowerment among users of mental health services. *Psychiatric Services* 1997; 48: 1042-1047
- ⁵⁹ Onken SJ, Craig CM, Ridgeway P, Ralph RO, Cook JA. An analysis of the definitions and elements of recovery: A review of the literature. Pre-conference paper prepared for the National Consensus Conference on Mental Health Recovery and Systems Transformation, Rockville, MD, December, 2004.