

XI. Requirements for Consumer Outcomes Measures

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Summary

There is a resurgence of interest in outcomes measurement and in trying to answer the question: “What differences do mental health services make?” Different stakeholders are interested in different outcomes: hence, many types of outcomes need to be monitored.

There are four major categories of outcomes: clinical outcomes, functional outcomes, outcomes related to life satisfaction/fulfillment, and welfare and safety outcomes. Several factors determine which outcomes are assessed: the purposes for which the outcomes will be used (i.e., treatment decisions, quality improvement, accountability, etc.); the intended audience for the information; the population to which the outcome applies; and the capacity of the system to gather, maintain, and analyze data.

Consumer outcomes measures have some advantages over system performance indicators. They tend to be more meaningful to potential users of performance measurement; more clearly represent the goals of the mental health system; and can provide a summary measure of the effectiveness of care across a variety of conditions and service types. Their disadvantages, however, are that they tend to be influenced by factors outside the control of the mental health system; may be insensitive measures for purposes of comparison, particularly if poor outcomes are rare (e.g. mortality rates); may require large sample sizes; may require obtaining data directly from consumers and family members; may require a long period of time to observe; and may be difficult to interpret if the care responsible for the outcome occurred in the past.

Many mental health systems already include outcomes measures. The scientific basis for outcomes measures exists and several standardized instruments are widely available. Implementation and burden issues are important determinates of the readiness for inclusion in a prototype information system.

Several areas require more work in the outcomes area:

- the relationship between a clinician’s assessment and a consumer’s self-report;
- the relationship of proximal outcomes such as improved functioning and symptom reduction to more distal outcomes such as employment and school performance;
- the reporting of aggregated outcomes taking into account case-mix adjustments;
- the most appropriate time periods between measurements, and whether these are the same for different instruments;
- the uses of outcomes data in treatment decision-making;
- methodologies for simplifying instruments and reporting;
- the development of different instruments for different sub-populations;
- calibration of instruments against each other;

- development of measures related to recovery and personhood;
- the relationship of recovery to other societal outcomes and service use;
- the definition of taxonomies and the operationalization of service modalities;
- research related to services and programs provided and the outcomes they produce.

XI. Consumer Outcomes Measures

What Is the Intended Purpose or Function of this Component?

The basic purpose or function of outcome measurements is to answer the question: What differences do mental health services make?

There is a resurgence of interest in answers to this question in an environment in which economics and costs are becoming significant determining factors. As managed care permeates healthcare systems and as healthcare reform policies are debated (including the issue of parity for mental health services), the “value” of mental health services is increasingly part of the consideration. What should be in the benefit package for mental health services? What is the marginal benefit of one additional outpatient visit? What difference does it make if a person is discharged after seven days instead of eight?

The answers to these questions have generally been in the realm of professional judgment. But as managers attempt to reduce the variation and unpredictability of the costs of mental healthcare, there is a search for more objective criteria. As the attempt is made to define what works best and most efficiently in specific terms, better definition and understanding of mental health outcomes are critical aspects of the solution. In the absence of good information on outcomes, decisions will continue to be made arbitrarily on the basis of cost, not necessarily because profit and efficiency are paramount, but because there is no objective mechanism to define quality.

Ultimately, outcome measures reflect the reason for the existence of a mental health organization. The organization exists to improve the functioning and lives of people with mental illness. Just as a business exists to produce profit, mental health organizations exist to produce better consumer outcomes. “Outcomes” are the currency and bottom line of a mental health organization. It is this realization that has created a new impetus for outcome measurement in the mental health field.

Managed care has been defined as a balance or reconciliation of quality, access, and cost. The purpose of such a balance should be to produce better outcomes.

For all stakeholders, the overriding reason to learn about the changes that have resulted from the services received or delivered is to ensure or improve the quality of care. If the services received by a consumer have not had a positive impact on his or her life, then it is necessary to determine why not and make adjustments that will lead to better outcomes. Different stakeholders, however, are interested in different types of changes.

Consumers are interested in whether the problems for which they sought services are being, or have been, addressed and whether the services have had an overall positive impact on their lives. Campbell (1994) points out that the goals of a mental health professional may differ from those of the consumer and that different priorities may be given to the same goal. Moreover, in some situations, the mental health professional and the consumer may view the same behavior in opposite ways. While the professional may see refusal to take medication as an expression of anger or the desire to maintain distance from family members as negative, the consumer may view these same phenomena as leading to growth, recovery, and independence. From a consumer perspective, there is also a high

priority on identifying negative outcomes that result from treatment such as medication-induced side effect, and debilitating trauma due to involuntary commitment, seclusion, or restraint.

Purchasers are interested in whether the services purchased are producing positive and expected results, and whether these are being produced efficiently. The question here is: Did the payer get value for money, i.e., Were fewer work days lost? Was “good” treatment provided? Were consumers satisfied? Purchasers may use such outcome information to make decisions related to selecting managed care organizations or providers and reviewing or renewing contracts.

From a management perspective, while there is always an interest in better outcomes for the consumers served, it is also important to determine how a program (or provider) compares with other programs (or providers) providing similar services, both in terms of outcomes and in terms of the relationship of outcomes to effort and costs.

Providers are interested in outcome measurement and associated benchmarks to assess whether treatment and services resulted in positive change, and, based on an evaluation of such changes, whether to maintain or modify the treatment regimen. Providers want to know how the outcomes for one consumer are related to outcomes for other consumers with similar characteristics.

These different uses for outcome measures are well captured in three terms suggested by Sperry and colleagues (1996): outcomes monitoring, outcomes measurement, and outcomes management. These terms indicate how outcomes can be used at an individual, program, and system level.

- *Outcomes monitoring* is the comparison of a consumer’s outcomes against a standard or expected result to determine whether progress is being made as anticipated. Outcomes monitoring is used to monitor change in an individual over time and to alter treatment when it is not producing desired outcomes.
- *Outcomes measurement* is the quantification of aggregated outcomes for many individuals. Data are used to compare services and programs, rather than to compare change over time in a single person to make treatment decisions.
- *Outcomes management* is the accumulation and use of information in a way that allows learning from experience and in which outcomes are used to reshape care delivery. For example, it is possible to profile providers by assessing improvement of consumers per session for a particular diagnosis.

In summary, outcome measurement has multiple uses for different stakeholders and is relevant to individuals, programs, and mental health care systems. At a clinical level, outcome measurement can be used in treatment planning and for determining and adjusting assignments to levels of care. These data, gathered at an individual level, can then be aggregated and incorporated into performance indicators and report cards at the system level. Not all system-level outcomes are aggregations of consumer-level outcomes: there are system outcomes related to resources, earnings, expenditures, and administrative processes that are independent of consumer outcomes, for example, reduced expenditures on inpatient services or increased Medicaid earnings.

What Information Is Required to Accomplish this Purpose?

Types of Outcomes

McGuirk and colleagues (1994) identified ten major outcomes: consumer satisfaction, consumer involvement, symptom reduction, improved social functioning, skilled coping, personhood, family relief, family involvement, safety, and community tenure. They based their list on input from consumers, family/friends, providers, and administrators, and noted that different stakeholders prioritized these outcomes differently. For example, safety issues were given much higher priority by providers and administrators than by consumers and family members. Symptom reduction and skilled coping were also more important to providers and administrators than to consumers. On the other hand, personhood (which included self-esteem and personal well being), consumer satisfaction, and family relief were more important to consumers.

Rosenblatt (1998) grouped a wide range of outcome measures into four major categories:

- *Clinical status outcomes* focus on impairment in both psychological and physical status. Measures of clinical status are defined as processes that document and assess the physical, emotional, cognitive, and behavioral signs and symptoms related to a disorder.
- *Functional status outcomes* are related to the ability to fulfill effective social and role-related functions. Examples of functional outcomes are the ability to work, attend school, live independently, and maintain positive and enhancing relationships.
- *Life satisfaction and fulfillment outcomes* include quality of life and well-being measures and are related to self-esteem, hope, quality of life, empowerment, and recovery.
- *Welfare and safety outcomes* include suicide, substance abuse, involvement with the criminal justice system, victimization, and homelessness.

A new trend — person-based or personal outcomes — which has currency in the developmental disabilities field is just beginning to have an impact on mental health. The Council on Quality and Leadership in Supports for People with Disabilities (1997) uses the following definition: personal outcomes are what people expect from the services and supports they receive. Personal outcomes refer to the major expectations that people have in their lives. The Council identifies twenty-five outcomes in the areas of identity, autonomy, affiliation, attainment, safeguards, rights, health, and wellness. The Council also recommends measuring how an organization supports personal outcomes in three areas: organizational learning (input mechanisms, quality improvement), organizational foundations (risk management, emergency procedures, consumer rights, dignity and respect, natural support relationships) and organizational stewardship (budgeting/accounting system, annual independent audit, information systems, staff training, etc.).

The Outcomes Roundtable for Children and Families (1999) argued that outcome-based accountability depends not only on describing outcomes, but also on linking them together. They proposed that three domains be addressed simultaneously: information about the population of concern; information about interventions; and information about the outcomes achieved by the interventions.

Selecting Outcomes

How are we to select from among all these possible outcome measures? Rosenblatt (1998) suggests choosing those measures that best assure a match between the characteristics of the consumers to be served, the goals of the service system, and the types of services to be provided. For example, a mental health juvenile justice system may want to focus on rearrests whereas a mental health system that provides services to adolescents may want to focus on school attendance or school performance.

Selection also depends on the functions that will be served and the perspectives that will be addressed by the outcomes measurement system. In fact, lack of consensus on which outcome measures to use can usually be resolved by clarifying the purpose of measurement and the stakeholder concerns and priorities that need to be addressed.

Scientific rigor is also a consideration in determining what information is required. For several outcomes, there are instruments with good psychometric properties and associated normative data. For others, the development of measures is in its infancy. The level at which scientific rigor is considered acceptable will determine whether any information *can* be gathered related to a particular outcome.

Within the mental health field, unfortunately, there are tremendous scientific and practical problems in knowing what to measure and how to measure it. Some of the limiting factors identified by Sperry and colleagues (1996) include the following:

- Approximately 40 percent of outpatients will probably improve without treatment, given enough time.
- The wide variety of theories of etiology and approaches to treatment create a divergence of opinion regarding what is important to measure.
- When combinations of treatments are used — for example, medication, individual therapy, and family/group therapy — it is difficult to determine which one(s) had an impact on outcome and to what extent.
- The wide variety of possible outcomes that can be measured requires decisions regarding which are most important to assess.
- Mental health diagnoses account for only four percent of the variation in outcomes. For example, although three people with major depression might take the same antidepressant, one may improve, one may remain the same, and one may get worse.
- Outcomes derived in experimental settings may not apply in real life.
- The time at which measurement should occur is not well defined. Should clinicians measure outcomes at the completion of therapy? Six months later?

- The administrative burden of obtaining outcomes information is increasingly an issue: it is time-consuming and costly for clinicians and consumers to answer questionnaires and complete forms to document the effectiveness of treatment.

In summary, several factors will determine *which* outcomes measures are used. First, how are these measures going to be used: for clinical purposes or for system performance measurement; for quality improvement or for marketing; for management functions or for contract monitoring? Related to how the measures are used is the audience for whom the outcomes measures are intended, and the priority the intended audience places on the outcome. For example, personal outcomes are a high priority for consumers while clinical outcomes may receive more emphasis from purchasers or managed care organizations. Third, the population to which the outcomes measures apply determines which measures should be used. There are different outcomes for children, for persons with serious and persistent mental illness, and for persons with episodic mental illness. Outcomes may be defined by type of problems, by type of setting, or by type of treatment. For example, specific outcomes may need to be defined for persons who have co-morbid conditions such as mental illness and substance abuse or mental illness and mental retardation and for persons with mental illness in a criminal justice setting or for persons receiving supported employment services. Finally, the capacity of information and administrative systems to gather, maintain, and analyze data for consumers at two points in time will constrain and limit the adoption and implementation of certain outcomes measures.

Proposed Measurement Sets

Several initiatives are underway to define a core set of outcomes measures for adults and children. One such initiative is the National Association of State and Mental Health Program Director's (NASMHPD) President's Task Force on Performance Indicators and Outcomes Measures funded by the Center for Mental Health Services. The outcomes measures now being used in a 16-state indicator study are:

- Consumer perception of outcomes
- School improvement
- Employment
- Functioning
- Symptom relief
- Adverse outcomes
- Consumer injuries
- Elopement
- Out of home placements
- Health status
- Recovery/hope/personhood
- Reduced substance abuse impairment
- Living situation
- Involvement with the criminal justice system

Who Provides the Information?

Outcome measurement generally involves collecting information at the beginning of treatment and at specified times during and after treatment using a particular instrument or scale. The sources of this information include the clinician, the consumer, a family member or friend, or a collateral provider (e.g. schoolteacher). How the information is obtained, from whom it is obtained, when it is obtained, and where and how the data are stored may vary widely.

Both the consumer's and the clinician's perspectives are important. The consumer perspective is essential for ensuring that the clinician's perspective is accurate and complete and therefore is an important aspect of treatment. Obtaining information from consumers increases the likelihood that the most significant areas have been covered; using standardized instruments to do so increases the likelihood that the results will be comparable with information obtained at a later time for the same consumer and with results obtained for other, similar consumers. Another advantage of collecting information on the consumer perspective is that it reduces the time clinicians spend on completing questionnaires or instruments.

The clinician's perspective is important in that it incorporates a professional assessment with the information provided by the consumer. This is especially important if treatment decisions are going to be made on the basis of the outcomes data. If treatment decisions are not involved and the outcomes measures are going to be used primarily at the program or system levels, a consumer's self-report may suffice. Information from a family member or friend or a collateral provider can enhance the scope and reliability of information, but may increase the burden of data collection.

In collecting outcomes information from providers and consumers, Eisen and colleagues (1999) suggest three stages: communicate with providers regarding the needs, purposes, and processes used in obtaining outcome information; involve providers in the decision-making process in designing and implementing outcomes measurement systems; and provide feedback to providers. We would strongly argue that the very same communication should occur with consumers. When information is obtained from either consumers or providers, issues of consent and confidentiality must be thoroughly addressed.

A second issue related to who provides the data is whether information is obtained for an enrolled population (i.e., the entire covered population whether persons receive services or not), all persons who receive services, or a sample of persons who receive services. The advantage of tracking an enrolled population is to identify the impact of *not* receiving services. For example, it would be possible to determine whether consumers who needed services but did not receive them were involved to a greater extent with the criminal justice system or were experiencing other negative outcomes. The major methodological problem that needs to be resolved for tracking an enrolled population is the identification of persons with mental illness. Another advantage of obtaining information on all enrolled persons or on all persons served is that outcomes measurement can be part of the administrative routines of enrollment and service utilization, thereby making outcomes monitoring and outcomes management easier.

If the intent is to assess periodically outcomes at a systems level, the use of a sample is a viable alternative. This, however, has another set of methodological problems including tracking whether a particular consumer is part of the sample or not.

Whether all persons served or only a sample are followed, measurement is needed at a second point in time. Research does not indicate clearly whether follow-up measurement should be at three, four, six or twelve months, although the outcomes literature suggests that the greatest amount of improvement tends to occur in the early stages of treatment. Eisen (1999) recommends that the second assessment be done between 30 and 45 days after the initial evaluation. Decisions related to follow-up intervals tend to be made on the basis of clinical judgment and administrative burden. Eisen points out that obtaining information at follow-up is more difficult than assessing consumers at intake.

In some situations, the source of information is not the clinician or the consumer but the administrative information system. For example, data related to mortality or incarceration in prison may be obtained from health department or department of corrections information systems or databases. The need for a unique identifier to link different data files is a key factor in being able to track consumers across multiple systems to determine the outcomes of care.

What Information is Produced?

At the level of the individual consumer, the information produced is the change in a score on the instrument used to measure the outcome that has occurred between a measurement made at time one and a measurement made at time two. The change score indicates whether the consumer is moving in a direction signifying improvement or in the opposite direction.

Unfortunately, many standardized instruments do not specify what change score constitutes “improvement.” Others, however, have normative data that can be used to determine whether a positive change has occurred. A reliability chance index can be used to determine whether a particular change has occurred by chance, but an index derived for a specific population may not be generalizable to other populations.

In some settings, clinicians are given information on change scores at specified times to inform their treatment decision-making. With new technologies, this feedback can occur almost instantaneously. Both clinician-reported and self-reported instruments are being used for clinical decision-making. Self-report instruments can be used to identify specific symptoms and problems, show broad areas of difficulty, shape treatment goals to address problem symptoms and areas of difficulty, and include the consumer’s perspective on symptoms and problems (Eisen, 1999).

Aggregation of outcomes data can occur at different levels, including a system or program level, for a specific grouping of consumers by certain characteristics, or for consumers who receive a specific service or combination of services. Outcomes can then be compared for similar groups or for similar services across different systems. Results can be presented in ongoing management reports, special studies, performance indicators, provider profiles, and report cards.

Who Uses the Information?

Outcomes data can be used by the entire range of stakeholders including consumers, family members, advocates, providers, managers, purchasers, researchers, and policy makers. Depending on the perspective, outcomes measures are used to determine whether the system or the consumer is doing

“well.” In the current environment, where cost has become a driving force, outcomes measurement is also a mechanism to ensure that quality is being maintained and improved.

How Ready Is the Component for Inclusion in the Information System?

Many information systems already include outcomes measures, although standardized instruments are not always used. The capacities of information systems are not a major limitation in this area as the scientific platform on which to build outcomes measures into information systems exists.

Implementation and burden issues are more important factors in determining the readiness of the outcomes component of the information system. The first step in implementation is to define the outcomes. In designing the outcomes system, factors that need to be addressed include selection and standardization of reliable and valid instruments; flow and periodicity of information updates; design of reports for various stakeholder groups; training for consumers, clinicians, managers, information systems specialists and policy makers in how to complete questionnaires and forms and how to use the results; and development of elements of the infrastructure that will ensure data completeness and quality. Our current state of knowledge and experience is such that the implementation of an outcomes system is feasible, but it requires leadership, commitment and resources.

What Future Efforts are Needed for Readiness?

Several issues require further exploration and resolution before outcomes measurement is fully ready for inclusion in an integrated information system. These include:

- the relationship between a clinician’s assessment and a consumer’s self-report;
- the relationship of proximal outcomes such as improved functioning and symptom reduction to more distal outcomes such as employment and school performance;
- the reporting of aggregated outcomes taking into account case-mix adjustments;
- the most appropriate time periods between measurements, and whether these are the same for different instruments;
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- the relationship of recovery to other societal outcomes and service use;
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- research related to services and programs provided and the outcomes they produce.

References

Campbell J. Toward collaborative mental health outcomes systems. *New Directions for Mental Health Services* 1996;71:69-78.

McGuirk F. The Horizon Institute's test of an outcome-based quality assurance model at the Mental Health Center of Boulder County, Inc.

Rosenblatt A, Wyman N, Kingdon D, Ichinose C. Managing what you measure: creating outcome-driven systems of care for youth with serious emotional disturbances. *Journal of Behavioral Health Services Research* 1998;25:177-193.

Council on Quality and Leadership in Supports for People with Disabilities, 1997

Eisen SV, Leff HS, Schaefer E. Implementing outcome systems: lessons from a test of the BASIS-32 and the SF-36. *Journal of Behavioral Health Services Research* 1999;26:18-27.

Hernandez M, Hodges S, Cascardi M. The ecology of outcomes: system accountability in children's mental health. *Journal of Behavioral Health Services and Research* 1998;25:136-150.

Sperry L, Brill PL, Howard KI, Grissom GR. Treatment outcomes in psychiatry and psychiatric interventions. In *Mental Health Practice Under Managed Care*. New York, Bruner/Mazel, Inc., 1996.