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THE FEDERATION OF FAMILIES FOR CHILDREN'S MENTAL HEALTH

This TIP sheet offers an introduction to performance and outcome measurement as it relates to assessing the quality and effectiveness of behavioral health care systems and programs. It covers: family involvement in the selection, implementation and evaluation of these measures; basic beliefs and values underlying outcome measurement; vocabulary of outcome measurement; suggestions for using outcome measurement data; and the family role in insuring the accountability of programs and systems.

UNDERSTANDING AND USING PERFORMANCE MEASUREMENT AS A TOOL FOR ADVOCACY

Family Advocacy And Performance Measurement

Advocacy means the act of pleading or arguing in favor of something, such as a cause, idea, or policy. Advocacy also means actively speaking for or giving voice in support of a cause, idea, or policy.

To be an effective advocate for an individual child or for all the children in a community or state, you must have some evidence about how the program or system you are concerned with is currently working. You need to know what it does well, what it does poorly, and what outcomes you want to improve. Performance measurement systems collect, analyze, and report this information. Advocates can use then use it to better understand how programs and systems are doing. Performance and outcome measurement can be used as a yardstick to compare a service or system to itself over time or to other similar services.

Every successful business, large or small, monitors the quality of its product and continuously improves its production system. The goal is to produce a product the public wants to purchase, get it to market at a reasonable price in good condition, and have it there when customers want to buy it. It is now becoming common practice to have similar expectations from human service systems. Local communities, states and national agencies, foundations, and insurance companies are requiring outcome-based reports from service providers and systems.

Families have a significant personal stake in understanding outcome and performance measurement systems, because their children's future depends on how well programs and services are delivered. Outcome and performance measurement systems can help families to know if a specific service is having the desired results. By being well informed about the performance measurement systems used in their communities and states, families can help insure that agencies, programs, and providers will be held accountable for the kinds of outcomes families value. Family members can use the results of outcome and performance measurement systems to advocate for the continued funding of programs and services that have positive outcomes for children and their families. They can use this information to recognize high performing programs as "best practice" for children and urge that less successful programs improve or be discontinued.

Advocating For Outcome And Performance Measurement

The results reported by most outcome and performance measurement systems are relatively objective and are generally accepted by policy makers and providers. Nevertheless, advocates for children with mental health needs and their families will want to know how outcome data is collected, who will be getting the results, and how the data and results will be used.

There are several ways that families can influence how outcome and performance measurement systems work. Families can:

- Support and promote the use of measures that give clear outcome information. They can identify items that are not useful and they can suggest items to add that get at issues families think are important. Some example items might be improvement in behavioral-emotional functioning, school functioning, and in child/parent satisfaction with services.
- Comment on the way data is collected and reported and suggest changes that better protect family privacy.
- Conduct consumer satisfaction interviews or surveys.
- Contribute to data interpretation and review of evaluation instruments.
- Be part of a group that makes decisions about program improvement based on information collected.
- Suggest evaluation data that should be widely distributed in the community—such as in newsletters and the media.
- Participate in evaluating the quality and usefulness of the outcome or performance measurement system itself.

Benefits Of Family Involvement

Family input is key to making certain that the tools used for outcome and performance measurement are respectful to families, are non-intrusive, and will reliably collect the information that is asked for. Families know which data really measure service, program, or system effectiveness and which items don't get to the real issues. For a service system to be truly effective it must focus on outcomes that impact the everyday life of a family—only families can say what these are.

Families bring a unique understanding and insight into the development of measurement systems. It makes sense to include these insights by actively involving family members at the beginning. Postponing family review and comment to the end of the process can lead to false assumptions or misinterpretation of the results. For example, an increase in the number of children referred to or enrolled in special education might be considered a negative finding by some, whereas parents whose children could benefit from special education services may see it as a positive outcome.

An important rule of evaluation and research is, "First, do not harm." Families will take care to insure that results are properly worded to avoid blame, shame, and stigma. Some examples of commonly used terms that families find offensive are: schizophrenic kids (rather than children

with schizophrenia), delinquents (rather than youth involved with the juvenile justice system), and dysfunctional families (rather than families facing multiple stressors).

Effectively including family input requires paying serious attention to diversity, strong and constant support, respect, and training. Cross training opportunities should be made available so family members can understand the needs of the agency that is collecting data. It is always important to consult with more than one family member.

Families know what policymakers need to hear. Family experiences and perspective combined with the results of outcome and performance measurement systems should have a significant influence on planning and policy development.

Increasingly, family members are saying, "Nothing about us without us!" They want to celebrate effective programs, services, and providers and advocate for improvements where needed.

Defining Outcomes And Performance Measures

Outcomes are the result or effect of supports, services or interventions.

Performance measurement provides an organized way to describe the outcomes achieved by systems, programs and service providers.

Every child's family has specific outcomes in mind when they seek mental health services and wants their child's services and providers to be working towards accomplishing those outcomes.

Most families can explain the outcomes they want for their children in simple and direct terms. Some typical examples are:

- to be living at home, to be in school and learning and to be out of trouble;
- to be healthy;
- to have friends; and
- to grow into a responsible adult.

Once the outcomes are determined and clearly stated, a performance measurement system can be designed to measure the desired outcomes. Performance measurement systems should continuously monitor the progress of each child and family.

Service providers, agencies, and states have some accountability concerns as well.

- Individual service providers want to know how well the children and families they work with are doing.
- The agency a provider works for has to make sure that the work being done is satisfactory.
- The agency is accountable to one or more funding sources - like a health insurance company, a foundation, a federal, grant or Medicaid. They want to know they are getting their money's worth.
- Providers and agencies are also concerned about meeting standards for licensing, certification, and accreditation.
- State human services departments monitor the way contracted agencies deliver mental health services and how they measure the outcomes of the services they provide.

Comprehensive performance measurement systems can collect the data necessary to do these as well as answer outcome questions from the families and communities being served. The bottom line in outcome-based accountability is how well children and families are doing and how well government funded services meet the interests of citizens and communities.

Basic Beliefs

It is important to have a set of principles to guide the development and use of a performance and outcome measurement system. The following values and beliefs should guide the development of these principles.

- Families are the frame of reference upon which any outcome measurement system should be based. All decisions about outcome assessment should be made with active and direct family participation.
- Differences in race, ethnicity, culture and language must be respected and addressed. The results of outcome measurement will not be meaningful if diverse family values about wellness, illness and treatment are not taken into consideration and incorporated in their development.
- There must be a commitment to using the results to continually refine systems and programs with the goal of making sure each and every child's quality of life improves.

Caution

All outcome measures have limitations and great care should be taken in the way data is interpreted and used. Particular care should be taken to insure that:

- Measurement tools are used properly. For example, graphs used to illustrate data should be clearly labeled and accurately reflect that data.
- Reasonable conclusions are drawn from the data collected. For example sample sizes should be large enough to give reliable results and measurement tools should be suited to the questions being asked.
- Real practical significance is a high priority. For example, even though the resulting data may be significant from a statistical perspective it may not have any relevance to families. If the outcome is not relevant to families and other stakeholders it may not be worth the effort to measure it.
- Care is taken to not over generalize the results. For example, if a measure was used with urban children only the results cannot be applied to a much wider and more diverse group. The population or group the results apply to needs to be precisely defined.

Principles

Principles should guide the development and use of a performance outcomes measurement system. Families, community members, providers and practitioners, and formally trained evaluators should all participate in deciding on the guiding principles for the system. Each community will define their own principles based on the scope of the performance and outcome measurement system they want and the resources they have available to collect data and conduct evaluation activities. Some principles to consider are:

- Always consider the child, family and caregiver viewpoint. Include what they say about how well their needs have been met. Ask them what they think about both the services and supports they received and about the people who provided these services.
- Consider the provider's viewpoint. Select outcomes and measures that are well matched to their strengths and also consider the limitations under which they work.
- Be true to the community's cultural values, attitudes, and beliefs. Use evaluation tools that are relevant to the community and are compatible with the diversity of its population.
- Select tools that are easy to use and adapt if needed.

- Conduct the evaluation (interviews, focus groups, surveys, and questionnaires) in the language or mode of communication preferred by the person responding.
- Collect data to assess outcomes periodically and document changes over time. Adjust for the normal developmental changes that will occur in the child during the interval between data collections.
- Link outcome data to the type of services and supports the child and family receives. Understanding the relationship between care provided and results helps families choose who they want to implement their service plan.
- Present the results of performance and outcome measurement in language and formats that can be understood and used by stakeholders engaged in system planning and improvement.

In addition, specific agency goals and having a research design and measurement tools that insure validity and reliability are important considerations in developing the principles developed for the performance and outcome measurement system.

Vocabulary

Performance and outcome measurement is a specialized field and has its own specialized words - its vocabulary. The most commonly used terms are defined here along with an explanation of how each term relates to the others. However, each performance outcome system may have its own definitions of these and other terms. Family members should ask their local system evaluator to explain the technical terms they are using and give examples that illustrate their use.

Some of the terms used in performance and outcome measurement are related to each other. We must understand the larger ideas to get to the specifics. Like the nested Russian dolls, you must open the larger dolls to get to the ones inside.

Domain—Domain refers to a large group or cluster of issues in the mental health system that have something in common. There are four most frequently identified domains.

1. **Access:** Is the degree to which services are quick and easy for families to obtain when needed. For example, how close is the service provider to the family and how available is that provider to see the family in a timely manner, without waiting lists?

2. **Appropriateness:** Is providing the family a choice from a large number of effective and desired services. These services must take into consideration the family's needs and fit with the family culture. That is, are the services tailored to fit what the family needs and wants? Are the services provided in a respectful manner and in the language the family uses? The services must also be provided by individuals who are skillful and in supportive surroundings that do not alienate the family.
3. **Quality:** Is the attention and priority that is paid to providing good care, that is, care that has been proven to work. It also means that family involvement is

Examples of Performance Indicators by Domain

1. **Access:** Out of home placements (such as in a residential treatment center or psychiatric hospital).
2. **Appropriateness:** Availability of providers that speak more than one language.
3. **Quality:** Family involvement in treatment planning and treatment.
4. **Outcome:** Change in how well a child or family is doing at home, school or work, as determined by an instrument or scale that measures behavior

valued and considered to be most important when making decisions about care and services. The goal is to improve the child's and family's quality of life.

4. **Outcome:** Refers to whether the services provided have had a positive or negative effect on the family's well-being or ability to function. Most often we refer to outcomes as the positive results that families want, need and should expect to receive as a result of services.

Performance Indicator—Performance indicators tell us how well a specific part of the mental health system is performing - whether we are getting the outcomes or results desired. Within each domain there will be a set of particular issue that families and communities think are the most important. There should be one or more performance indicators for each of these questions or issues.

There are two broad categories of performance indicators. **Common** performance indicators are general and are of interest across different systems, situations,

and groups of people. For example, child well-being is an indicator that is common to both the mental health and child welfare systems. **Core** performance indicators apply to a particular system or group. For example, reading level is a core indicator for evaluating the performance of a school system. Change in clinical symptoms is a core indicator of interest to mental health clinicians and health insurance companies.

Performance Measure—Performance measures are like thermometers - they take the temperature of the system. Performance measures show the degree to which an indicator is present in the system. Performance measures are usually expressed as a ratio with a numerator and denominator. There should be one or more performance measures for each performance indicator. For example, one way to measure the indicator *out of home placements* in the *access domain* is to divide the number of children not living at home (numerator) by the total number of children who get mental health services (denominator). This calculation would give the percentage of children who get mental health services and who are not living at home. See figure 1 for this formula.

A different measure of *out of home placement* would be to divide the number of children in therapeutic foster care or residential treatment centers by the total number of children who live in the community (called a catchment area). The choice of numerators and denominators strongly influences the outcome reported by the measure. Therefore, family members and other advocates should pay particular attention to them and ask evaluators and researchers why particular numerators and denominators were used.

The a ratio or percentage calculated by a performance measure can be used to track changes in a program's or system's performance over time and to compare programs or systems with each other. It can also be used to describe how a particular child and family are doing and show any changes since the last time the indicator was measured.

There are two broad categories of performance measures as well. **Process** performance measures show how well a system operates. Some examples are:

- Client or family satisfaction with such things as:
 - convenience of the provider's location
 - ease of scheduling and making appointments;
 - communications with staff; or
 - the services they received.

- The range or types of services offered;
- How often requested services are denied; or
- How long it takes to get community services after discharge from a psychiatric hospital.

Outcome performance measures can be sub-divided into three categories. **System outcomes** tell how well the entire system is functioning. **Program outcomes** tell how well specific mental health programs are doing. **Clinical outcomes** tell how well individual children and families are functioning as a result of services.

To summarize, domains are the overarching issues in the mental health system that are important to know more about. There are four frequently studied domains: access, appropriateness, quality and outcomes. Performance indicators are specific issues within a domain that tell about how well the mental health system is performing. Every performance indicator needs to be measured. The performance measure is usually calculated as a ratio or percentage. The ratio or percentage can indicate performance at a single point in time or show change over time.

Reporting Results

Just like a child's report card from school, program and system report cards are a way of informing families and the public about the results of performance measurement systems. Report cards use information from performance indicators and performance measures along with data from other sources (like billing records or satisfaction surveys), to make an overall evaluation of a system or program. Report cards sometimes assign "grades" to programs or systems so that family members can rate performance and choose the program or system that best meets their needs.

Results should be broadly disseminated in language and formats understandable to families, providers, policy makers, administrators, funders, and any other group that has an interest in the program, service, or agency being evaluated. This can be done through media reports such radio and television news broadcasts or newspaper articles. This can also be done through newsletters to family organizations, at parent and teachers association meetings, conferences on children's mental health, or state and local mental health council meetings.

Figure 1
Formula for a Performance Measures

Domain =	Access
Indicator =	Out of home placements
Measure =	$\frac{\text{Number of children placed out of home}}{\text{Total number of children who get mental health services}}$
Outcome =	Percentage of children who get mental health services in an out of home placement

Examples Of Outcome Measurement Tools

There are nationally used outcome measurement tools that can be used by family members for advocacy purposes. Two that are available for every state are the Mental Health Statistics Improvement Project (MHSIP) and the State Mental Health Block Grant.

State Mental Health Block Grant—It is important that family members and consumers know how their state measures up in satisfying federal requirements for providing mental health services to children, youth, and families. Each state has a Mental Health Advisory Council which has consumer and family members. This council assists in the developing the state's mental health plan and in evaluating its implementation. This plan describes in detail how the state will spend millions of dollars it receives as a State Mental Health Block Grant from the federal government. State system performance goals are incorporated into these plans. At the end of the year, each state prepares an implementation report showing how the money was actually spent and the progress made toward achieving the goals set out in the original plan. These documents are available for public scrutiny.

Advocates can use them to comment about they way federal dollars are spent for public mental health services in their state.

MHSIP—produces a Consumer Report Card. The data collection instruments for the MHSIP Report Card include the Youth Services Survey for Families. This is a federally tested and validated tool that is widely used to measure family and youth satisfaction with a specific mental health program from which a youth is receiving services. It is a process measure in the outcome domain and looks at improvement in functioning. Family members can help in the administration of the survey and in compiling and analyzing the results. They can insure that the results are published and are made available to families. Advocates can then provide feedback and make sure that their recommendations are acted upon.

Last Words

Families and their children are directly affected by how well or how poorly a program or system performs. Therefore, families and youth must play a role in determining the outcomes desired, the appropriate indicators of those outcomes, and the measures to be used for insuring the accountability of programs and systems that serve them. While these may be different from those chosen by funders, policy makers or providers, the outcomes, indicators, and measures chosen by families will accurately reflect what families need and want.

When families have good information about the performance of a program or system they can make informed decisions and choices. Families can make choices about the mental health system they sign up with, the providers they see and the services they use. They will have the tools they need to advocate for improvements to the mental health system.

Examples of system outcome performance measures

- How accessible and available are services to families;
- The quality of the continuance of care. For example, when children transition from residential treatment to home and community are the services available and appropriate and are they provided without interruption;
- How well community agencies collaborate when they are all providing services to one family.

Examples of program outcome performance measures

- The number of children served in a program;
- How much it costs to serve one family in one year;
- How much any one service, such as case management, is used by a program.

Examples of clinical outcome performance measures

(usually based on a rating scale or something like it)

- Change in symptoms (usually a reduction);
- The child or family is doing better at home, school or work;
- The child is now living at home instead of a residential treatment center or psychiatric hospital;
- The child is no longer involved in the juvenile justice system.

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