

Data Matters

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Outcomes in a System of Care

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Outcomes and outcome management are gaining increasing attention in children's services as stakeholders at all levels of involvement want to know the impact of services. Consumers want to know if the mental health service will improve their lives; agency and clinical providers want to know if their treatments are effective; purchasers of services want to know if what they are paying for is of any value. In a system of care, outcomes have many "masters" requiring measurement at different levels of the system and in different child-serving systems.

A well-integrated outcome measurement system will include outcomes at multiple levels—system, program, and clinical, and across multiple systems—health and behavioral health, juvenile justice, child welfare, and education. **System outcomes** involve the structure and processes of the service system and include such outcome domains as access, continuity of care, interagency collaboration and comprehensiveness. Measurable outcomes might include penetration into target communities, timeliness of getting an appointment, cross-agency collaborative activities or shared funding strategies. **Program outcomes** tend to involve administrative data, such as number of children and families served, cost per case and utilization. **Clinical outcomes**, a critical element in an outcomes systems, may include clinical symptoms, behavioral and cognitive functioning, social and interpersonal functioning, family functioning, restrictiveness of living situation, school performance or involvement with the juvenile justice system. In addition to these outcomes, **client or family satisfaction** is garnering increasing attention as an important dimension to measure. Satisfaction measures focus on process factors such as convenience of location, ease of scheduling and accessing appointments, clinician and staff responsiveness

and communication, and cost and billing procedures. These variables, important to children and families, are often not represented in other outcome domains.

Children with complex mental health needs often require services across different systems. Yet each child-serving system collects data to support its own particular outcome system and the outcome data across these service systems are often poorly integrated. Child welfare outcomes include safety, permanency and well-being measured by outcomes such as incidences of child abuse or neglect, number of placements, or successful adoptions. Juvenile

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OHIO Takes A Statewide Approach to Outcomes

Dee Roth, M.A.
*Chief of Program Evaluation & Research
Ohio Department of Mental Health*

The State of Ohio has been involved in a five and a half year process to develop, test and promulgate outcomes measurement for persons in its community mental health system. The journey began with a blue-ribbon task force convened by Ohio Department of Mental Health Director Michael Hogan, PhD, and charged with developing a comprehensive, statewide approach to measuring outcomes. The 42-person Outcomes Task Force was composed of many constituencies—providers, adult consumers, families of child and adult consumers, local mental health boards, advocates, academic researchers and state staff—and worked diligently for 16 months. Although it was their initial desire to go right to the selection of measurement instruments, the group instead started by determining those types of outcomes that they

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justice outcomes may include recidivism rate, probation violation, or number of contacts with law enforcement. School outcomes may include attendance reports, academic performance, or reduction of suspensions.

Confronted with the task of measuring and tracking outcomes, states, local communities and provider agencies are developing different outcome measurement plans. While it is acknowledged that outcome systems must be tailored to the specific, targeted community, there is a movement in the field to try to standardize outcomes and performance measures so that different programs, systems and states will be able to “talk” with one another and ultimately, monitor, track, compare and identify the best array of services for a child with complex behavioral health care needs.

In this issue of **Data Matters**, we provide examples of federal, state and local efforts to develop useful outcome systems at multiple levels and across different service systems.

- At the federal level, the **Substance Abuse and Mental Health Services Administration** (SAMHSA) has initiated several efforts to identify and gain consensus on behavioral health outcomes, measures, and performance indicators for children and adults.
- The **State of Ohio** embarked on a statewide approach to develop, test and disseminate outcomes measurement for their community mental health system.
- **The Children’s Mental Health Benchmarking Project** collects administrative data from states and counties to enable cross-jurisdiction comparisons on various indicators.
- **The Dawn Project**, a local system of care project in Indiana, systematically developed multi-system goals and outcomes and specific indicators for school, child welfare, juvenile justice, mental health and family outcomes.
- The **Family Perspective** is essential to understanding outcomes in a system of care. Two articles articulate this perspective and the need for outcomes to be meaningful in the real, day-to-day context of family and community.
- The article on **Data Disparities** addresses the importance of culture in determining an outcome system. Outcomes need to be meaningful to the target group and reflective of cultural differences and expectations.
- In systems of care, children receive services in multiple systems. Several articles preview outcome measurement efforts in the **child welfare, education, and primary health care systems**.

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The Children’s Mental Health Benchmarking Project

Sylvia B. Perlman, Ph.D., Sara L. Nechasek, M.M.,
and Richard H. Dougherty, Ph.D.
Dougherty Management Associates, Inc.

The goal of the Children’s Mental Health Benchmarking Project is to gather, compare, and disseminate administrative data from states and counties in order to enable policy makers to compare their own jurisdictions to others with regard to certain key indicators. Although billions of dollars are spent every year on providing mental health services for children, very little is known about how various systems allocate their resources, how they use state and federal funds, or what difference any of these variations make. Comparative administrative performance data can often inform and facilitate analysis and decision-making on policy changes at the state and county level. Dougherty Management Associates, Inc. (DMA), a research and consulting firm, received support for this project from the Annie E. Casey Foundation, the Center for Health Care Strategies and The Robert Wood Johnson Foundation.

For this project, DMA asks state and county agencies to provide administrative data on a series of measures; DMA then standardizes these data to enable comparisons across the sites. Making comparisons is still challenging, however. The indicators and measures must be carefully defined to maximize the likelihood of receiving equivalent data. For the purposes of this work a “measure” is a specific data element used to calculate an indicator. An “indicator” is a standardized calculation used to point to quality or performance. A “benchmark” is a standard for comparing the performance of mental health systems.

Each jurisdiction has its own system for providing and funding mental health services for children, and even for dividing responsibility between its mental health authority (MHA) and its Medicaid agency. Examples of the many elements that may vary include funding, financing methods, benefits, population demographics, and type of managed care system. For these reasons, comparison of data between sites should be considered preliminary, and used only to identify areas for further inquiry or quality improvement.

The project focuses on developing data on a set of core indicators in the **domains of access, utilization, expenditures and intersystem involvement**. Using these indicators, the project seeks to answer three basic questions:

- How many children are served?
- In what settings?
- At what cost?

In the year 2000, nine states, three counties and the District of Columbia submitted data. During 2001 a revised version of the data collection instrument was sent to 50 state MHAs, most state Medicaid agencies, and selected counties. Thirty-six different jurisdictions—31 states, four counties and the District of Columbia—submitted data in the second year; eighteen provided both MHA and Medicaid data. The data submitted enabled DMA to compare a number of indicators across jurisdictions.

The project’s findings suggest significant variation among states and counties on most of the dimensions examined. Highlighted below are key indicators; one from each of the domains:

- **Access: Children served per 1,000 population**

The average number of children served by 26 MHAs, per 1000 population under 18, was 19.3, while the average number of children served by 25 Medicaid agencies, per 1000 population under 18, was 21.2.

- **Utilization: Mental Health Authority Inpatient Days per 1,000 Population**

The rates of inpatient days per 1000 population served by 20 MHA's ranged from 1.6 to 69.8, with a mean of 24.7 days. Variability in these rates may be attributed to the inclusion of different types of inpatient psychiatric facilities in the data. (See Figure 1)

- **Expenditures: Inpatient expenditures as a proportion of total expenditures**

Sixteen MHAs devoted, on average, slightly more than 22 percent of their expenditures to inpatient hospital care and 78 percent to all other types of services. Twenty-one Medicaid agencies reported a

similar average (24%) and range of expenditures for inpatient care. The proportion of inpatient expenditures for MHAs ranged from one percent to 62 percent, while for Medicaid agencies the proportion was also similar, ranging from three percent to 58 percent.

- **Intersystem Involvement: MHA Percentage of Children in Out-of-Home Placement**

Nine sites reported on the proportion of children who received MHA services and were in foster care or other out-of-home placement during the year. These rates ranged from 4.1% to 16.7%, with a mean of 10.5%.

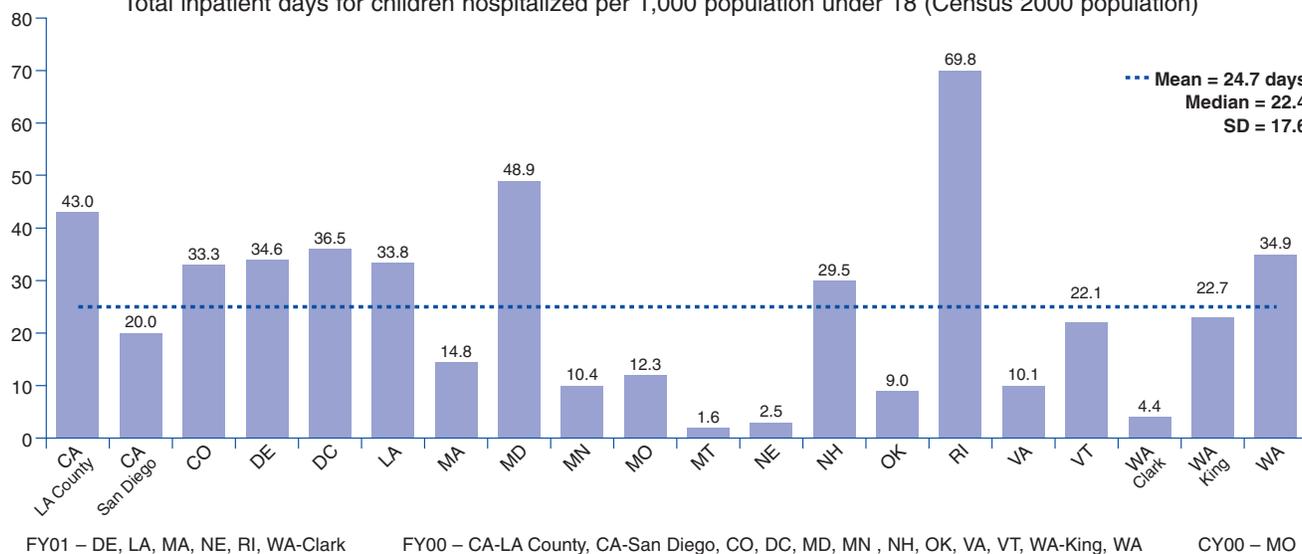
The Children’s Mental Health Benchmarking Project has taken a lead, along with MHSIP and NASMHPD in their 16-state study, in collecting comparable data directly from state officials. Our experience can inform others who are involved in developing and using common indicators. At the state and local levels, stakeholders can compare themselves to others, thereby enhancing their understanding of their own systems and ultimately their ability to make positive changes. At the national level, no other initiative has yet published comparable public data specific to children’s mental health services. Nor has any other project systematically included both MHA and Medicaid data. We look forward to continuing gathering data in this third year of the project.

For more information contact Richard H. Dougherty, Ph.D., Dougherty Management Associates, Inc., 781-863-8003, public@doughertymanagement.com, or visit our Web site, www.doughertymanagement.com

FIGURE 1

Mental Health Authority: Inpatient Days per 1,000 Population

Total inpatient days for children hospitalized per 1,000 population under 18 (Census 2000 population)



Ohio Takes A Statewide Approach continued from page 1

felt consumers in the mental health system should be achieving. When those were determined, the group then established the criteria they would use to screen all existing instruments, e.g., the extent to which they addressed the desired outcomes, their level of burden for both providers and consumers, their psychometric properties, their cost, their level of cultural competence, and whether they were recovery/resiliency focused.

The outcomes chosen fell into four domains: symptom distress, quality of life, functioning, and safety and health. The group struggled initially with the issue of whether the desired outcomes for adults and children were different, or whether both groups needed to achieve the same kinds of outcomes but with different ways of measuring whether they had been achieved. They embraced the latter view, and then went on to the thorny process of instrument selection. The Office of Program Evaluation & Research did a literature search and came up with 126 potential instruments for the Task Force to review—a daunting task! They found that there were many outcomes instruments for adults, but they tended to be very specialized in content, and most were in the public domain; whereas there were fewer available instruments for children, they tended to be fairly comprehensive, but almost all were proprietary, which would mean a monetary cost to provider agencies.

The task force ended up constructing an adult instrument that was a composite of other tested instruments, either in whole or in part, plus a few added questions. For children, they chose the CAFAS (Child and Adolescent Functional Assessment Scale), the BERS (Behavioral and Emotional Rating Scale) and the FES (Family Empowerment Scale.)

In mid-1998, the Department convened another group of individuals (volunteer local systems, including providers, mental health boards, adult consumers and family members of child and adult consumers) to oversee a full test of the instruments and the overall workability of the Outcomes System. It included the management of the process, how consumers and families of child consumers understood the instruments and experienced the process, the level of cost and burden, the psychometrics of the instruments and the use and transport of the data. The understandability of both sets of instruments was found to be very high, and, interestingly, both adult consumers and families of child consumers had a lot of ideas about how the data could be used. Case managers and other staff indicated that they were positive about the outcomes measurement process but felt less sure about how to use the data.

The overall feedback about the child instruments that had been selected was negative. The three instruments were felt to be burdensome by both parents and staff, and the cost of the instruments and the needed training was

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THE DAWN PROJECT: 500 Kids, Five Years, and Still Counting

Knute Rotto, A.C.S.W., CEO
Choices

Five years and 500 youth and families later the Dawn Project continues to provide the individualized, strength based, family centered and culturally appropriate care for which it was designed.

The Dawn Project (Dawn) was created in Marion County, Indianapolis, Indiana and began serving youth and families May 1997. Dawn was formed to coordinate and deliver services and resources across multiple child-serving systems (county child welfare and juvenile probation, and state departments of special education and mental health). The mission of the Dawn Project remains to provide new and improved levels of help and assistance to children with serious emotional disturbances and their families. The children served have been involved in at least two child serving systems, have been in or are about to be placed in residential treatment and have functional impairments that cause them serious difficulties in home, school and community.

To support the mission, the Marion County Office of Family and Children (MCOFC), Juvenile Court, Division of Special Education and Division of Mental Health (the payers) contracted with Indiana Behavioral Health Choices (Choices), a non-profit entity, to manage the clinical and financial processes and/or outcomes of Dawn. Choices **blends** dollars across child-serving systems and creates integrated child and family **teams** to deliver high quality services and support for Marion County children with serious emotional disturbances and their families. Choices developed a community **resource** network, which uses a **strengths** based approach to serve the families and children. Choices uses a technological infrastructure that provides financial and clinical accountability to state and county public systems, payers, service providers, and children and their families.

With all of that said, you might ask, “Have the outcomes been met? Is Dawn successful?” My answer is that it depends on what your measurement of success is. Measuring success is one of the most difficult things to do because each stakeholder has a different definition for success.

Prior to the addition to the Evaluation Plan guided by the requirements of the CMHS federal grant awarded in 1999, Dawn developed a local evaluation plan guided by

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FIGURE 2

THE DAWN PROJECT

Outcome Measures

Adopted February 13, 2002

GOAL #1: Provide high quality care, which results in improved outcomes for the child and family.

OUTCOMES

- I. Improved child and family functioning
 - A. Improved school functioning
 1. Grade reports, attendance reports, behavior reports, suspension/expulsion reports
 2. The Clinical Manager Treatment Plan level rating
 - B. Improved records with the child welfare and the juvenile justice system
 1. % of families with no further substantiated incidences of child abuse or neglect, which results in removal of the child from the home during involvement.
 2. % of families with no further substantiated incidences of child abuse or neglect, which results in removal of the child from the home for a period of six and twelve months from disenrollment.
 3. % of children with no further incidences of delinquency, runaway or truancy charges, or violation of terms of probation, which results in placement failure during enrollment.
 4. % of children with no further incidences of delinquency, runaway or truancy charges, or violation of terms of probation which results in placement failure for a period of six and twelve months from disenrollment.
- C. Improved records for community supervision for Department of Corrections youth
 1. Number of youth with arrests for offenses more severe than original offense
 2. Number of youth with arrests for offenses less severe than original offense
 3. Number of youth with technical violations other than for placement

4. Number of youth with technical violations that include placement failure
5. Number of youth with technical violations for placement failure only.
6. Number of youth with arrests in first year after disenrollment
- D. Improved CAFAS scores
 1. Measured with CAFAS at intake, every six months, and discharge
- E. Progress on Service Coordination Plan
 1. Measured by monthly team report and The Clinical Manager Treatment Plan level rating
- F. Fewer days in out of home placement
 1. Measured by Dawn national evaluation placement data
- II. Increased family autonomy
 - A. Decrease in number of paid providers
 1. Measured by service usage and payment data
 - B. Caregiver Strain Questionnaire
 1. Measured by Questionnaire at intake, every 6 months until discharge, and 12 months after discharge

GOAL #2: Include parents/families in decision making

OUTCOMES

- I. Parents/families feel more effective
 - A. Measured by Family Assessment Device at intake, every 6 months until discharge, and 12 months after discharge
- II. Caregivers are committed to plan
 - A. Measured by team meeting attendance
- III. Services meet the real needs of the child and family
 - A. Measured by biennial, narrative report of successes and barriers based on Service Coordinator focus groups

GOAL #3: Decrease the cost of serving children/youth with the most disturbed and disturbing conditions in Marion County

OUTCOMES

- I. Decreased cost per child
 - A. Comparison of actual cost for first three months and last three months of enrollment
 - B. Total restrictive services package changes and becomes less over time
 1. Measured by comparing units of three most restrictive services for first three months vs. last three months
- II. Child and family receive cost effective services:
 - A. Measured by service utilization data
 - B. Measured by average cost per child—separated by grant and non-grant populations

GOAL #4: Be accountable to all stakeholders

STAKEHOLDERS INCLUDE:

Payor Groups

Marion County Office of Family & Children
Marion Superior Court, Juvenile Division
Indiana (DOE) Division of Special Education
Indiana (FSSA) Division of Mental Health & Addiction

Consortium Members

Parents/families
Children/youth
Mental Health Association in Marion County
School systems in Marion County
City County Council
Dept. of Corrections
Mayor's Office
Service Providers
Families Reaching for Rainbows

MEASURE

- All stakeholders agree that the above outcomes and their measures encompass the areas most important to them
- All stakeholders agree on the method of reporting outcomes to them

The Dawn Project continued from page 4

the Community Consortium. The Community Consortium, made up of stakeholders and representatives of the payers, family members, and representatives from local schools, state hospital, corrections, providers, local health and mental health centers, identified an Outcome Committee to look at outcomes, demographics, and other measures that would help the Consortium decide if the Dawn Project was “working” or “successful”. Three years ago, the first outcomes were created, but proved difficult to measure. The Outcome Committee reconvened for the past 6 months to continue to examine our definitions, the data we gather, and our data interpretation. As a result, the Outcome Committee revised some outcomes and created a whole new set of indicators to measure (see Figure 2). As we continue to re-work and re-fine our evaluation plan, I have to believe that this struggle and process for “outcome definition”, measurement, and agreement across service systems and community stakeholders is common—and vital. Outcomes and evaluation is a work in process—and a process at work.

Family Outcomes: So, what are the families’ and youth perspectives on Dawn and outcomes for themselves? In our business, families and youth are the customers and their measurement of success is whether they are “better” after Dawn. From a family perspective, the majority of the families have stated, by survey, direct report, and feedback from Rainbows, a family advocacy and support group, that their involvement with Dawn helped them to be stronger parents, to become more educated about their family, and to find resources for life long support. Families talk of the difference in their lives that Dawn has made by listening and being there, offering support, and coordinating child and family teams that tap the family’s strengths to determine appropriate services. Dawn helps families handle

competing demands from different systems and through unconditional care, adjusts the plan of care rather than blaming a family for any intervention failure.

Program Outcomes: Should the program outcomes be either cost related, clinically focused, service defined or all of the above? Some indicators of what Dawn has accomplished over the past 5 years fall into each of those categories. Dawn has retooled existing “braided” funds from the various child serving systems into services and resources, sustained that effort for 4 years without a rate increase, and stayed within budget. Dawn has expanded the array and scope of services available to families and children and achieved statistically and clinically significant improvement in CAFAS (Clinical Adolescent Functional Assessment Scale) scores across all populations for 12 months. Dawn has “real time” clinical and cost information about youth served for quick plan adjustments and has systematized the flex funding process so teams can access flexible funds for families within 10 minutes. Dawn has expanded the populations served to include child welfare, education and probation youth, supported the growth of a family advocacy and education organization, and built a service coordination mechanism that affords a “best practice” level of eight families per worker to maintain continuity of care for families.

So, what do you think? Would you rate Dawn a success with the family and program indicators described here? I believe if you can synthesize the requested (desired) outcomes of all stakeholders into a common framework then you are closer to measuring “success” in your community. ♦

For more information contact, Knute Rotto, ACSW, CEO Choices, 317-205-8202, Krotto@Kidwrap.org or visit their website at www.Kidwrap.org

Ohio Takes A Statewide Approach continued from page 4

felt to be prohibitive. As a result of the evaluation information, a major shift was made in the child instruments to the Ohio Youth Problem, Functioning and Satisfaction Scales Short Form. This instrument, which has versions for the parent, the agency worker and the youth (age 12-18), had been developed when the Outcomes Task Force was meeting, but did not yet have complete psychometric testing, so was reluctantly eliminated from consideration even though it was judged to have better coverage of the important outcomes for children than the package that was chosen for testing. However, by the time the pilot test was coming to a close, the psychometrics on the Ohio Scales had been completed and proved to be excellent, and it is a much simpler and less costly instrument package to use.

After the pilot test, the workgroup concentrated on developing a number of products that would help other

local systems to put the Ohio Mental Health Consumer Outcomes System into place. Products included a Procedural Manual, an Implementation Planning Checklist that walks local systems through each step in the process from the beginning planning through training and data collection and use, and a Data Entry and Reports Template. The Template is a piece of software that runs off Microsoft Access and has three components: a set of data entry screens, a database that formats data for transmission to the state, and a set of reports that clinicians can use in treatment planning with individual consumers and families. From the earliest days of the Outcomes Task Force, there was a deep realization that if the information was not useful at the clinical level, the whole process would have missed its most important goal—to have feedback about outcomes guide treatment planning so that work would take place around trying to achieve those outcomes. The Template

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THE FORUM ON PERFORMANCE MEASURES IN BEHAVIORAL HEALTHCARE AND RELATED SERVICE SYSTEMS

Creating a Platform for Consensus and Progress

John Bartlett, M.D., M.P.H., Executive Director
The Forum on Performance Measures

The Forum on Performance Measures in Behavioral Healthcare and Related Service Systems is a joint initiative among the three centers of the Substance Abuse and Mental Health Services Administration (SAMHSA): Center for Mental Health Services (CMHS), Center for Substance Abuse Treatment (CSAT), and Center for Substance Abuse Prevention (CSAP). The overarching purpose of the Forum is to develop common approaches to the development, testing, and adoption of performance measures in behavioral healthcare and related services.

The idea for a SAMHSA-sponsored meeting focused on performance measures began in 1999 with the convening of the Summit Planning Work Group (SPW). The SPW's mission was to launch a consensus-based initiative that would identify a few performance indicators that all behavioral health organizations might share in common. The SPW proposed a forum—or platform for consensus—for recognizing and building on the contributions of agencies and organizations already engaged in the development of empirical measures of access, appropriateness, and outcomes of behavioral care (see page 19, Web-Based Sources).

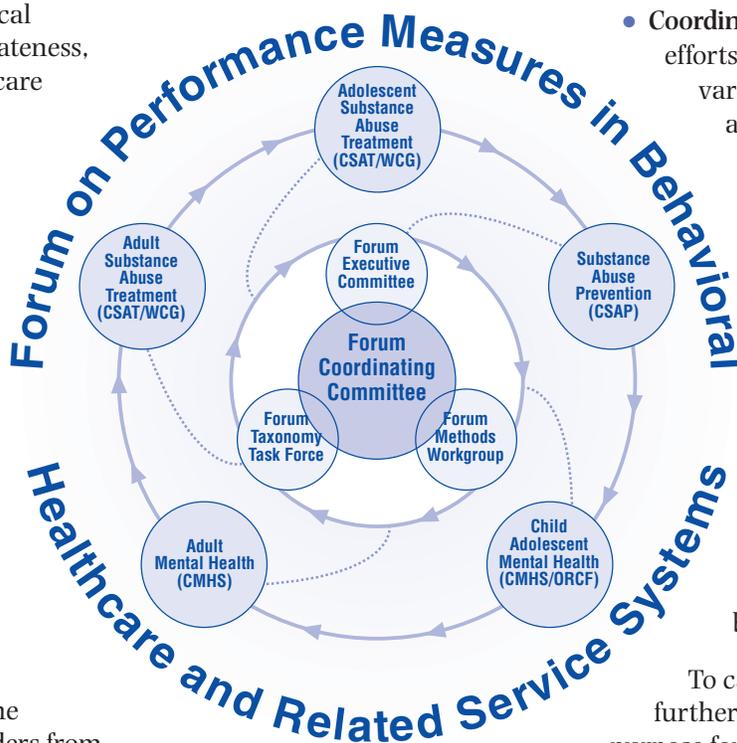
In March 2001, SAMHSA gathered representatives from a variety of existing public and private work groups at the Carter Center in Atlanta. The purpose of this gathering was to share and assess progress on the development and implementation of performance measures in behavioral health care and related service systems. The exchange of ideas and information shared among the representatives and stakeholders from

adult mental health treatment, adult substance abuse treatment, child and adolescent mental health treatment, and adolescent substance abuse prevention highlighted the past and current efforts in the area of performance measures and outcomes. In addition, the meeting succeeded in defining the significant overlap in both the content and process that has guided each group's separate efforts in this field to date.

In recognition of this common ground and these common interests, the participants agreed that the forum constituted an important and worthwhile venue for the coordination and mutual support of the existing efforts. Thus, the Forum on Performance Measures in Behavioral Healthcare and Related Service Systems became a unique entity with the following functions:

- **Identification and synthesis** of issues which are faced by the field of performance measurement in common, irrespective of area of focus (e.g., a common selection and testing process for measure development; model database architectures; and cross-cultural implementation)
- **Coordination and communication** of efforts and progress among the various separate initiatives already working in the field
- **Representation** of the overall Forum and the area of performance measurement to the field of behavioral healthcare at large and to other audiences
 - **Focus** of the overall efforts of the field on the successful implementation of performance measures within delivery systems, both public and private.

FIGURE 3



Created by Ann Doucette

To carry out these functions and further establish its identity and purpose for expanding the work

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Creating a Platform continued from page 7

highlighted at the Carter Center, the Forum crafted a mission statement, identified goals, and developed an infrastructure.

- **Mission Statement**

The mission of the Forum is to improve the delivery of behavioral health treatment and prevention services by supporting the development and adoption of broadly applicable indicators and measures to assess organizational performance and consumer outcomes. These indicators and measures should be designed to serve the needs of both external accountability as well as internal quality improvement. The Forum will provide an ongoing venue for collaboration, coordination, and communication between the various initiatives, both public and private, which are already working separately to measure service access and delivery, quality, and outcomes. The Forum will foster the sharing of information and experiences of provider, government, employer, consumer, and accreditation groups in implementing performance and outcome measurement practices and initiatives.

- **Goals**

1. Within each major area of behavioral health treatment and prevention, the Forum seeks to identify, develop, and implement common indicators and measurement specifications that are applicable to both public and private organizations and service delivery systems.
2. Across the major areas of behavioral health, the Forum seeks to promote the broad use of common approaches to performance and outcome measurement that will be useful for decision making through the provision of empirically sound and meaningful information on key points in the process of, and outcome of care or service delivery.
3. Across the fields of behavioral health, the Forum seeks to promote the development and sharing of knowledge about methodologically sound measurement practices that support the cost-effective implementation of performance measurement and the efficient, meaningful, and effective use of information (data) to improve care, services and outcomes.
4. Across the fields of behavioral health, the Forum seeks to provide a vehicle for the identification and elaboration of emerging and strategic issues in the area of performance measurement for organizations and systems of care and services.

- **Infrastructure** (see Figure 3):

The Forum is facilitated by a 15 member Forum Coordinating Committee that holds monthly conference calls and meets quarterly. The Coordinating Committee facilitates and coordinates the work of a combination of permanent workgroups and more time-limited task forces.

- The permanent workgroups, many of which antedate the establishment of the Forum, include:
 - Child and Adolescent Mental Health Workgroup (CMHS/Outcomes Roundtable for Children and Families—ORCF)
 - The Adult Mental Health Treatment Workgroup (CMHS)
 - The Adult Substance Abuse Treatment Workgroup (CSAT/Washington Circle Group—WCG)
 - The Adolescent Substance Abuse Treatment Workgroup (CSAT/WCG)
 - The Substance Abuse Prevention Workgroup (CSAP)
- The time limited task forces and workgroups currently include:
 - The Taxonomy Task Force
 - Forum Methods Workgroup

The Forum on Performance Measures in Behavioral Healthcare and Related Service Systems will hold its second meeting in the winter of 2003. ♦

For more information, contact Dr. John Bartlett at the Forum offices in Atlanta (404-942-3616) or e-mail him at johnbartlett@performancemeasures.org

MOVE **ON**
 to read **3** about *of the*
Forum workgroups
on pages 9 and 10.

THE OUTCOMES ROUNDTABLE FOR CHILDREN AND FAMILIES

Outcomes Accountability Within Child Service Systems

Ann Doucette, Ph.D.
Co-chairperson

The **Outcomes Roundtable for Children and Families** (ORCF) is sponsored by the Center for Mental Health Services (CMHS), Substance Abuse Mental Health Services Administration (SAMHSA). The **mission** of the Outcomes Roundtable is to bring together multiple perspectives and expertise to provide leadership that stimulates culturally competent and data driven improvements in policy, practice and research for children and adolescents with emotional and behavioral health needs and their families. This mission underscores the Outcomes Roundtable's **current focus** on the development of an appropriate outcome accountability system within child service systems. Presently, there is little unity across child-service systems on how to accomplish this, and virtually no means of sharing information across these systems. In response to this dilemma, the Outcomes Roundtable is working to identify a parsimonious set of consensus-based, behavioral health (mental health and substance abuse) performance measures that can be implemented and commonly **shared across child service systems** in both the public and private sectors.

In order to work effectively, the Outcomes Roundtable for Children and Families has organized itself into two workgroups:

The **Family Involvement/Education and Outreach** workgroup is charged with developing and disseminating information about the Outcomes Roundtable and its activities and products and supporting active engagement of families in Outcomes Roundtable efforts and activities. The primary focus of this workgroup is to increase the knowledge base of family members through education and training programs, to provide coaching and support in understanding scientific and professional reports, and to establish family/professional partnerships. The members of this workgroup will develop and maintain links and feedback opportunities between families participating in Outcomes Roundtable activities and families served by the behavioral healthcare system. This workgroup also serves as a liaison, through the dissemination of information, to

appropriate representatives of organizations, agencies, and professional associations that represent the public and private child service sectors.

The **Data/Methodology/Measurement** workgroup focuses on the development and/or identification of a proposed set of common performance measures for child behavioral health. This proposed set of common performance measures builds on a variety of existing frameworks and systems for example, the Institute of Medicine (*Crossing the Quality Chasm*), NCQA/HEDIS, FACCT (Foundation for Accountability), the American College of Mental Health Administration, Washington

Circle Group, and others. This workgroup is also charged with identifying gaps in existing frameworks and developing performance measures to address these gaps. To achieve this goal, the workgroup will identify operational definitions, measures, and measurement approaches for each proposed performance measure. This workgroup will also identify the criteria on which to judge the significance/meaningfulness, the scientific soundness, and feasibility of

implementing the performance measure. Additional activities include identifying potential opportunities for pilot testing selected performance measures.

In order to accomplish the objective of identifying a parsimonious set of consensus-based performance measures for potential use across child-service sectors, the Outcomes Roundtable for Children and Families, (under the auspices of CMHS/SAMHSA), is participating in a national Forum on Performance Measures in Behavioral Healthcare and Related Service Systems. In addition to the Forum related activities, the Outcomes Roundtable for Children and Families is currently involved in contributing to and strengthening the child and family focus of the MHSIP (Mental Health Statistics Improvement Program) Report Card, as well as working with other agencies in the development of new frameworks, and the revision of existing performance measurement efforts. ♦

For more information on the Outcomes Roundtable for Children and Families please contact the co-chairs: Ann Doucette, adoucette@aol.com and Trina Osher, tosh3@comcast.net.



THE WASHINGTON CIRCLE GROUP

Subcommittee on Performance Measurement for Care of Adolescents with Substance Use Disorders

Doreen A. Cavanaugh, Ph.D., Chairperson
Washington Circle Group Subcommittee on Performance Measurement for Care of Adolescents with Substance Use Disorders

The Washington Circle Group (WCG) was established in 1998 to develop and pilot test a core set of performance measures for adult substance abuse treatment services for public- and private-sector health plans and to collaborate with a broad range of stakeholders to ensure widespread adoption of the performance measures by health plans, private employers, public payers, and accrediting organizations. In January 2002, the WCG established a subcommittee on Performance Measurement for Care of Adolescents with Substance Use Disorders. This new subcommittee shares the Washington Circle Group's belief that there is a clear need to promote quality and accountability in the delivery and management of alcohol and other drug abuse services by organized systems of care, both public and private. The Adolescent

subcommittee also believes that, because adolescents may receive services in a number of different settings it is critical to extend their work to other related systems as well. Currently the subcommittee is focused on adapting three adult substance abuse process of care measures developed by the WCG. The subcommittee is also conceptualizing and specifying additional adolescent substance abuse treatment process of care measures.

The subcommittee coordinates its work with the Outcomes Roundtable for Children and Families as well as through the Forum on Performance Measures in Behavioral Healthcare and Related Service Systems. The work of the WCG Adolescent subcommittee will be discussed in future editions of Data Matters. ♦

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THE TAXONOMY TASK FORCE

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New Mexico Children, Youth, and Families Department Member, Taxonomy Task Force

For the past several years, numerous behavioral healthcare organizations (ACMHA, AOW, NCQA, CMHS) with extensive membership in both public and private sectors have been developing systems of indicators for evaluation. This work has developed in response to increasing demands for accountability at all levels. Although they had much in common, the information they gathered and the way they gathered it was different. While each organization served an important function there was no order among them, no crosswalks to enable comparisons and no identified measures in common that might unify the field.

Representatives involved in these earlier and ongoing efforts participated in the forum "Summit 2001: Reaching Consensus on Performance Measures in Behavioral Healthcare" hosted by SAMHSA and convened at the Carter Center in Atlanta, Georgia in March 2001. One of the key issues identified at this forum was the need for

concurrent development of common performance indicators not only for adults but also for children/families as well as the substance abuse and prevention areas. A more specific and fundamental challenge identified by the group was the wide variety of terms and an even wider variety of definitions for those terms that exist.

To address the large issue of term definitions, the Forum Coordinating Committee established the **Taxonomy Task Force** (TTF) to develop common definitions for all the terms associated with the broader task. Such terms as performance indicator, performance measure, common, core and many others need common definitions. The TTF is in the process of culling over the many definitions in current use for all the relevant terms. Some examples of the work in progress all prepared in draft form for review are as follows:

- **Common Indicator**—an indicator that represents an aspect of performance that is of widespread, even universal interest or concern across different organizational contexts and populations. Distinguish from Core Indicator.

- **Core Indicator**—an indicator that represents one of the most central and critical aspects of performance of interest or concern to a particular stakeholder perspective. Core indicators for one stakeholder group typically differ from the core indicators for other stakeholder groups. Distinguish from Common Indicator.
- **Indicator**—something important to measure; the markers that could identify an outcome target
- **Measure**—mechanisms used or data elements identified to support a judgment on the indicator

Through biweekly conference calls, the TTF continues the task of crafting definitions that capture the exact meanings intended and can be commonly used by the broadest range of stakeholders in the behavioral healthcare field. Once reviewed and approved, this resulting set of common terms and definitions will make the actual task of arriving at a common set of performance indicators achievable. The TTF expects to have a draft taxonomy ready for review in early summer 2002 for the Forum Coordinating Committee. ♦

Nothing About Us Without Us A Perspective on Outcomes for Families

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Family members may have a very different view of what the term “outcome” means. While professionals speak of performance measures and systems outcomes, families grapple with the daily challenges of insuring the survival of their families.

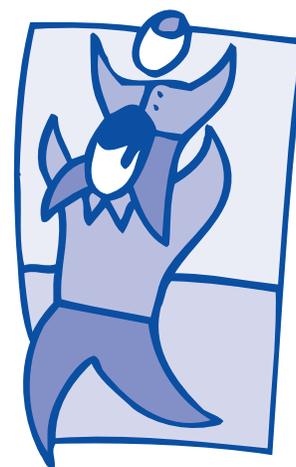
Families sometimes use a set of measures that are not reflected in the program or clinical manuals. How many times did I get called from the school this week or how many meals were we able to share together without interruption? Did the meetings with all the various agencies in our lives, the intensive therapy sessions and their evaluation requirements, allow us time to be a family and to practice the suggested behavioral modification? Are we closer to a path of healing or further away? Are our days filled with crisis management and financial burdens beyond our limits? Are our children headed toward a bright future with possibility and potential within the boundaries of their respective diagnoses or are they headed into the agency abyss to be lost to limited lives? Will they be alive? Will they survive the systems set in place to help?

These are the very real performance measures in our daily lives.

First and foremost, we seek safety for our children. We need to be assured that the standards of practice are based on the individualized needs of our family. We need to know that “practice” does not mean that our children are at the disposal of drug companies in collusion with research projects that experiment at the expense of our children's

lives. We need to know that when we find our sons or daughters in need of self-protection that the environments they are placed in will, first, do no harm. We need policies that insure suicide prevention means that they are in a safe space without access to items that they could use for self harm. One-to-one observation should be adhered to and not the common practice of periodic checks at the discretion and convenience of staff. We need strict enforcement of standards around restraint and seclusion. We have measured the outcomes at the gravesites of our children. The first outcome we seek is for our children to live.

The next outcome we seek is for our children to have a **quality of life** that insures their ability to be happy and productive members of their community. How do we measure that? We measure that by some of the same indicators that the research world uses. We measure that by success in school and progress in their educational plans. We measure that by our children's presence within the juvenile justice system, out of home placements, and community-based services. But we also measure by the number of times we have had “emergency” visits to doctors and therapists in a month. We measure that by nights at the supper table together without conflict. We measure by our own set of indicators; sharing a ceremony or celebration, being “in this together” or making it through a school suspension while adjusting to a new medication. As family members we need our strengths



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Commentary on a Framework for Outcomes and Accountability from a Family Perspective

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As primary care givers and key stakeholders, families of children with mental, emotional, or behavioral disorders are committed to insuring positive outcomes for their children as well as positive outcomes and accountability for a system of behavioral health care for children and youth.

The variety and number of possible and desirable outcomes is far greater than can reasonably be incorporated into a single efficient evaluation system. Each purchaser and provider has its own philosophy and reasons for using specific strategies and approaches to provide mental health and substance abuse treatments, services, and supports for children, youth, and families. This will, to a significant extent, determine the possible outcomes for treatment and services. For example, an approach that focuses only on medication management for a child cannot be expected to change the dynamics of relationships within the family. On the other hand, when the medication is working effectively, the child may be more attentive in school and be getting better grades. The process used to choose which outcomes to measure must, from the outset, fully and meaningfully involve a variety of family members who are raising children with mental, emotional, or behavioral disorders.

Families want the same ultimate outcomes for ALL their children regardless of their diagnosis or label, their individual strengths and needs, the services and supports they receive, and the systems that serve them. Families want their children to get better—to be able to live at home, to go to school and get good grades, to enjoy friends and activities in the community, and become responsible adults living independently. Any system of care should be designed to improve the ability of children, youth, and families to function in the natural settings of their communities. Successful and accountable systems must focus on outcomes that have these real life impacts.

Determining desired outcomes for children and families, as well as service systems, is an essential first step in developing an accountability system. In addition to supporting the process of developing an individualized intervention plan, a framework of outcomes can be a tool for designing and implementing the behavioral health care system itself. Behavioral health care system planners need

to know what changes they want to achieve before they design the system or a data collection system for measuring the outcomes. Behavioral health care accountability systems should continuously monitor the status of the children and families receiving services to see if they are making progress towards the desired outcomes.

A **framework of desired child and family outcomes** must:

- Address basic functional aspects of life such as physical health and safety, security and emotional stability, competence and independence, social interaction, and educational growth.
- Have both the capacity to describe and measure change over time and the flexibility to adapt to the stages of a child's development.
- Be fine tuned to the specific characteristics and the needs of children, youth, and families in different communities.
- Be culturally relevant and respectful of family values and beliefs about wellness, illness, and treatment.
- Include community leaders and families as sources of information to evaluate data collection instruments and interpret data once they are collected.
- Be considered within the context in which they occur or are observed and all the different places children spend their day, namely the home, school, or community.
- Focus on the basic unit of the child and family with individual plans of care that include outcome expectations and a systematic plan for measuring progress toward achieving these outcomes
- Use aggregate data—both qualitative and quantitative information from the individual to the group to the system as a whole—to contribute to an assessment of a program's effectiveness.
- Examine the interconnected relationships between outcomes and their impact on systems change.

The most important question is how will the outcome data be used? Who will be getting information about outcomes and what will they do with it? The only legitimate answer, from a family perspective, is to improve services and supports to children and families. This means

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Factors Contributing to Data Disparities in Research and Evaluation Efforts

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The need to view data and outcomes within the context of ethnically and racially diverse communities has never been more critical. Public system recipients are becoming more diverse as a result of an increasingly multicultural America, while inequities in access to services and quality of care continue to produce poor outcomes for culturally diverse populations. Recent reports, including the Surgeon General's supplemental report, *Mental Health: Culture, Race, and Ethnicity*, continue to highlight these disparities and the lack of system capacity to meet the mental health needs of diverse populations.

Within this context, data specificity for race and ethnicity is essential for determining meaningful outcomes, building culturally competent programs, and contributing to system change. For outcome

measurement, the data collected must be applicable to all populations yet sensitive to specific characteristics of each population. Data disaggregated by specific populations will provide more valid information regarding outcomes for culturally diverse populations. However, the outcome measurement system and the interpretation of the data must be conducted in the cultural and experiential context of the target community. For example, cultural considerations must be taken into account in the determination of outcomes, the selection of instruments, the strategies for collecting data, and the interpretation of the results. Failure to attend to these issues may lead to disparities in data and, ultimately, to meaningless outcomes and erroneous conclusions.

In assessing the potential for data disparities, attention must focus on barriers to involvement in research and evaluation for culturally diverse populations, appropriateness of research/evaluation tools, racial and ethnic categories, data analysis, and relevance of the findings. Some of the key issues in each dimension are highlighted in the following table. ♦

Factors Contributing to Data Disparities In Diverse Communities

Participation in Research/Evaluation	Reluctance of culturally diverse individuals to participate in research/evaluation efforts given historical concerns and the perception of the process as intrusive and potentially exploitative
	Limited fluency and familiarity with the English or dominant culture language
	Lack of recruitment and training of bilingual and/or bicultural data collectors who are from the communities served
	Lack of awareness and understanding of the importance of research and evaluation
	Lack of formal partnerships between researchers and community based organizations that can function as "bridges" for the community
Research/Evaluation Tools	Limited relevance and applicability of the questions and measurement tools for ethnically and racially diverse communities
	Limited availability of standardized instruments normed for specific populations and socio-economic levels
	Limited availability of the instruments in different languages
Racial and Ethnic Categories	Minimally defined federal categories for race and ethnicity that contribute to the exclusion of specific populations from participation or data analysis
	Mis-match between self-reported individual ethnic and racial "identity" and race/ethnicity selection options
	Mis-identification of the individual's race or ethnicity by researcher/observer
Data Analysis	Aggregate data profiles that obscure potential trends in diverse communities
	Misinterpretation of responses resulting from lack of understanding of the cultural context
	Exclusion of specific populations due to small sample sizes when data are disaggregated
Relevance of the Findings	Presentation of the data generalized to the predominant culture ("one size fits all" approach limits applicability to culturally diverse groups)
	Findings that do not address outcomes that are meaningful to culturally diverse communities

Commentary on a Framework continued from page 12

that outcome information needs to be shared with all stakeholders: the people who are providing services so they can maximize their intervention; the families so they can celebrate achievements and advocate for modifications as needed; the program managers so they can make informed administrative decisions; and the public so the community knows what value it is getting for its investment in mental health services for its children, youth, and families.

In the end, the only acceptable outcome is an improved quality of life for the children and families served. System outcomes that are not based on the experiences of families fail this critical test of truly holding providers accountable for the outcome of their work. ♦

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acknowledged, our resources valued and our children treated with love and respect.

A “**systems**” outcome often denotes the measurement of a certain “system” or way of doing things. In some Native cultures those systems outside of the tribal community may be suspect. Remember that our history has given us reason to question the purpose and implications of studies. Institutionalized racism has been present since our first dealings with researchers in anthropology and sociology, often leading to devastating governmental policy regarding our children. Behavioral expectations and differences within our respective cultures may not fit with the standards embraced by the general population. When Dylan is seen as defiant because he refuses to participate in a program that is in direct violation of his cultural values, such as not becoming engaged in competitive activities, or Charlene is counted as truant when she is adhering to commitments designated by her clan, assumptions are made that do not fit the “system” in place in these children’s lives. Children may be seen as having behavioral problems simply because the behavior does not “fit” within the context defined as “normal” within another system. Most instrumentation does not reflect the individual differences and definitions within differing cultures. When measuring a “systems” outcome it becomes critical that these issues are addressed.

In the community in which my first child was born, the native language was the first language spoken. When the children entered the school system many had limited English proficiency. There were no words in the native tongue for certain concepts and most of the teachers were from an outside culture. When recess came all the children would simply leave the school grounds and go home, some would return later, many would not. The parents did not see this as problematic, as children were not forced to do anything they would not choose to do. If something was deemed to be dangerous then it would be discouraged but

otherwise they had the freedom to explore life on their own terms. Within their own system this all worked perfectly well but when intersected with another system, conflict arose.

Families have learned that some “systems” work better than others. We can tell you what those systems are that are not helpful. We can tell you that giving up custody to the state in order to access the financial support for services is not helpful. We can tell you that “systems” set up to punish instead of instruct are not helpful. We can tell you that when our natural resources, our cultural norms, or our definitions of family are not supported, it is not helpful.

Many of us do feel there should be “nothing about us, without us.” We need to be at the table when the performance measures and systems outcomes are being developed. We need to “partner in order to prove” what our experience has taught us. Our tribal communities have learned that effective measures and best practices must include our traditional healers and spiritual leaders. At the same time we need to be conscious of the fact that “standard” evaluation tools that gather information in a respectful and reliable way have yet to be developed. We need our informal community supports to be included in the therapeutic measurements.

We need programs that include **culture at the core of care**. This may mean a horse club, traditional harvesting and gathering, drum and dance societies, or clan and language retention. In non native communities it could mean martial arts, faith based activities, a local boys and girls club or any number of formal and informal activities that are based in the village in which the child lives. We need the development of tools that fit with our cultures and communities. We need to document what works. When Joe rides a horse and it calms him to the point that he is able to perform better at school, or when Angela practices martial arts and she is better able to control her impulsive behavior, we know it makes a difference. Remember, it is we who sit at the dinner table, attend the parent teacher conferences, or are called to court to account for the actions of our children.

Often times the resources within cultures and communities are ignored in evaluation despite the significant role they play in both the quality of life and the progress toward successful outcomes. As a result many effective community based initiatives are not supported and are seen as insignificant. We need our strength and knowledge coupled with the skills and tools of the research and evaluation world to insure inclusion of these resources to foster true outcomes change for our children.

The outcomes we seek ultimately will be measured by future generations. We have a belief in my community that the decisions and actions of today will impact seven generations to come. Our children and our children’s children will decide whether we have done that in a good way. ♦



Improving Outcomes for Children and Families Served by the Child Welfare System

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Over the last five years, the Department of Health and Human Services (DHHS) has launched several new approaches to monitoring State child welfare programs. These approaches reflect an increased focus on improving outcomes for children and families, as opposed to solely monitoring compliance with procedural requirements, as had been the case in the past.

The **Adoption and Safe Families Act of 1997 (ASFA)** called for DHHS, in consultation with State and local public officials, advocates, and other experts, to develop a set of outcome measures to be used in assessing the performance of State child welfare programs, and to report to Congress annually on the performance of each State. ASFA established three national goals for children in the child welfare system—**safety, permanency, and well-being**. The set of outcome measures created to assess States' performance in achieving these goals include the following:

- Reduce recurrence of child abuse and/or neglect
- Reduce the incidence of child abuse and/or neglect in foster care
- Increase permanency for children in foster care
- Reduce time in foster care to reunification without increasing re-entry
- Reduce time in foster care to adoption
- Increase placement stability
- Reduce placements of young children in group homes or institutions

ASFA required that, to the extent possible, the outcome measures should rely on data available from existing data systems. The two national data systems that States are reporting to include the Adoption and Foster Care Analysis and Reporting System (AFCARS) and the National Child Abuse and Neglect Data System (NCANDS). However, one drawback of utilizing the existing data systems is that data are not available to measure the outcome of well-being.

A focus on well-being, in addition to safety and permanency, is incorporated in a new form of federal

oversight by DHHS called *Child and Family Services Reviews* (CFSR). Regulations for this approach to monitoring State child welfare programs became effective in March 2000. Overseen by the Children's Bureau of the Administration for Children and Families (ACF), the reviews consist of a statewide assessment as well as an on-site review, which is conducted by a team of Federal, State and peer reviewers. During the on-site review, the team conducts case record reviews, interviews with children and families receiving services, and interviews with community stakeholders. The following outcomes are examined as part of the review process:

- **SAFETY 1**—Children are, first and foremost, protected from abuse and neglect
- **SAFETY 2**—Children are safely maintained in their homes whenever possible and appropriate
- **PERMANENCY 1**—Children have permanency and stability in their living situations
- **PERMANENCY 2**—The continuity of family relationships and connections is preserved for children
- **WELL-BEING 1**—Families have enhanced capacity to provide for their children's needs
- **WELL-BEING 2**—Children receive appropriate services to meet their educational needs
- **WELL-BEING 3**—Children receive adequate services to meet their physical and mental health needs

The reviews document areas of strength and areas needing improvement. States then have the opportunity to implement program improvement plans and to receive technical assistance in making the improvements.

The provisions of ASFA and the Child and Family Services Reviews are reflective of the new level of accountability being required of public agencies nationwide. Ultimately, the goal for all of these efforts is to enhance States' capacity to achieve positive outcomes for the children and families they serve. ♦

For more information, visit the Children's Bureau website at <http://www.acf.dhhs.gov/programs/cb/>

Aligning School Accountability, Outcomes, and Evidence-Based Practices

Howard Adelman, Ph.D. and
Linda Taylor, Ph.D., Co-Directors,
*UCLA School Mental Health Project/
Center for Mental Health in Schools*

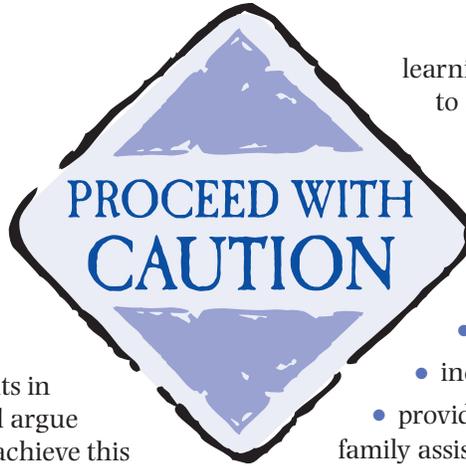
The Elementary and Secondary Education Act reauthorization underscores the pressure on policymakers and practitioners to improve schools utilizing evidence-based practices that promise rapid improvements in student achievement test scores. Few will argue against implementing practices likely to achieve this outcome. However, prevailing reform strategies are not yet comprehensive enough to raise achievement test averages continuously over the long run, particularly in low performing schools. Sustained school improvement outcomes will require (1) developing a more comprehensive approach to education reform, (2) expanding the framework for school accountability and desired outcomes, and (3) rational use of the evidence base.

Expanding School Reform: A Comprehensive Approach to School Improvement

School improvement efforts have been limited to a two-component approach focused on (1) enhancing instruction, and (2) improving governance and management of resources. This approach is limited by:

- failure to reform and restructure school-based and associated activities used to address factors that interfere with student performance and learning;
- piecemeal development and categorical funding of student support programs and services; and
- fragmentation and marginalization of the planning, implementation, and evaluation of efforts designed to enable learning among students experiencing barriers to learning.

School improvement frameworks need to be expanded to incorporate a third “learning supports” component that addresses barriers to learning as a high priority and identifies a continuum of interventions encompassing healthy development, prevention of problems, early interventions, and systems of care. In our work with schools, we translate this continuum into a multi-level approach consisting of student, family and school-wide support programs, services and practices that enable



learning. This enabling component is designed to address barriers to learning and promotes healthy development by encompassing interventions to:

- enhance classroom-based efforts to enable learning
- respond to and prevent crises
- support transitions
- increase home involvement in schooling
- provide individually-tailored student and family assistance
- promote greater community involvement and support, including recruitment of volunteers.

Expanding the Framework for School Accountability

Development of such comprehensive approaches to address barriers to learning also will require adoption of an expanded framework for school accountability. Demands for rapid gains in achievement test scores currently drive school improvement planning. Thus, the prevailing accountability measures pressure schools to narrow their focus and adopt oversimplified and oversold strategies. The focus on test scores disconnects school improvement planning from the realities of what it takes to improve academic achievement in low performing schools.

An expanded accountability framework should encompass a continued emphasis on high academic standards, but it must also include measures of what schools are accomplishing in terms of promoting students' social and personal functioning, as well as benchmarks for measuring progress in addressing barriers to learning (e.g., improved school attendance, fewer behavior problems, increased family involvement).

A Caution About the Evidence Base

Adopting a more comprehensive approach to school reform and expanding our definition of school accountability should stimulate the development of an evidence base that encompasses a broader range of meaningful outcomes and demonstrates the value of education support programs. This is a crucial next step given that existing data to guide comprehensive school improvements are sparse and often only suggest promising directions, particularly with respect to approaches for

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Measuring and Monitoring Community-Based Systems of Care

••• THE M&M PROJECT •••

Diane D. Behl, M.Ed., Richard N. Roberts, Ph.D.,
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The development of comprehensive, coordinated, culturally competent, community-based systems of care for children with special health care needs (CSHCN) and their families is the overall goal for *All Aboard the 2010 Express: A 10 year Action Plan to Achieve Community-Based Service Systems for Children and Youth with Special Health Care Needs and their Families*. The six core outcomes as listed in the action plan serve as the foundation for this effort and require strong partnerships among families, communities, state, and the federal government. These include:

1. Families of children with special health care needs will partner in decision-making at all levels and will be satisfied with the services they receive;
2. All children with special health care needs will receive coordinated ongoing comprehensive care within a medical home;
3. All families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need;
4. All children will be screened early and continuously for special health care needs;
5. Community-based service systems will be organized so families can use them easily;
6. All youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

(The 2010 Express action plan is available at www.health.gov/healthypeople.htm)

What is the M&M Project?

The Measuring and Monitoring Community-based Systems of Care Project is a five-year project funded by the Federal Division of Services for Children with Special Health Needs and is a collaborative endeavor of Early Intervention Research Institute (EIRI) at Utah State University and six states: Vermont, South Carolina, Ohio, Arizona, Utah, and Oregon. The purpose of the project is to understand current state capacity to measure these CSHCN outcomes and to help them enhance their capacity through

expanded measurement and monitoring efforts. Measurement enables states to make data-based decisions on where to focus efforts as well as how to set short and long-term objectives to reach the six outcomes. Monitoring progress on the six outcomes through a valid and reliable measurement process will help to keep the vision on track, and provide important information on what is working and what needs further attention.

Who are CSHCN?

Children with Special Health Care Needs (CSHCN) are defined as those children and youth who have or are at risk for chronic physical, developmental, behavioral, or emotional conditions that require health and related services of a type or amount beyond that required generally for children. It is estimated that 16-18% of the population of children ages birth to 21 fit within this definition, including children served by state Title V programs as well as children served by early intervention, special education, mental health, and developmental disabilities offices, and other programs to support children with special needs.

What can states do to enhance their own measurement capacity?

In partnership with the six states, EIRI facilitated a Participatory Action Research (PAR) approach to guide measurement efforts in each state. PAR is a method for conducting research whereby decisions are made by a team of key stakeholders consisting of families, community providers, and policymakers from the various programs within Title V as well as other departments, such as Education, Developmental Disabilities, and Medicaid. States that establish such teams are better poised to develop data collection methods that are practical as well as family centered. Individually and then collectively, the six state PAR teams achieved consensus on a set of indicators to help operationalize the measurement of these six outcomes. One example of an outcome and agreed upon indicators is:

Outcome #1—Families of children with special health care needs will partner in decision making at all levels, and will be satisfied with the services they receive.

Indicators:

1. % of families reporting satisfaction with the quality of: regular source of primary care, obtaining

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addressing barriers to learning. For example, while there is growing evidence on how to engage students in learning to read, a comparable body of research has not been produced clarifying how to *re-engage* students who have become disengaged from classroom learning. The tendency in such cases is to focus on the misbehavior that often is associated with disengaged students and to rely on evidence-based practices oriented mainly towards social control. However, these practices are not necessarily effective and, in some cases, may be counterproductive with respect to re-engaging students in the learning process.

Given the magnitude of what schools must do each day and the range of learners with whom they must succeed, educators have little choice but to design much of what they do by extrapolating and interpreting a diverse body of empirical and theoretical literature. Clearly, they should always seek out the best practices available; at the same

time, we should continually strive to identify and evaluate outcomes of comprehensive, multi-faceted, and cohesive learning supports to ensure that every child has an equal opportunity to succeed. ♦

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The following materials available on the website may be of particular interest: *A Sampling of Outcomes from Interventions Related to Addressing Barriers to Learning* (Technical Assistance Sampler); *A Center Brief: Addressing Barriers to Learning and Promoting Healthy Development: A Usable Research Base* (Center Brief); *Enhancing Classroom Approaches for Addressing Barriers to Learning* (Continuing Education Module); and *Evaluation and Accountability*.

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referrals and appointments for needed services, coordination among primary care specialty care overall services.

2. % of parents who report satisfaction with their level of involvement/input in setting concerns and priorities to make decision about their child's care plan.
3. % of parents who report knowing the steps to take when they are not satisfied with the services their child/family receives.
4. # of parents who are supported financially for their involvement in state and local activities.
5. # of parents who report that they are effective partners in policymaking at the state and local levels.

The six pilot states are using the indicators to guide their measurement and monitoring efforts. They enhanced their capacity to measure and monitor these indicators through a variety of strategies, such as:

1. **Using national and state-level surveys.** Surveys can be particularly helpful in measuring the outcomes for the broader population of children with special health care needs, going beyond those enrolled in state CSHCN programs.

2. **Data warehousing and data integration.** A data warehouse is a collection of client data compiled from several programs based on a static point in time. Data integration is a method of collecting and tracking information on specific individuals though the development of an active or "live" unified data system. These types of data sharing efforts can broaden a state's system of care by helping agencies, both public and private, see children with special health needs as "our children".
3. **State CSHCN continuous program improvement tools.** State CSHCN programs have developed strategies to learn more about how their program meets the needs of children and families served through their clinics and supported activities. Some examples include: incorporating the measurement of the six outcomes into program enrollment and update forms; records review procedures; and family satisfaction surveys. ♦

Visit our website: <eiri.usu.edu/projects.htm> for publications by the M&M project. For further information, contact: Richard N. Roberts, richr@cpd2.usu.edu or Diane D. Behl, behld@cpd2.usu.edu. Call toll-free 1-800-887-1699.

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Copies of **Data Matters** may be distributed freely. If you would like to contribute to future issues or if you have suggestions/corrections for the mailing list, please send information to:

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Prior and current issues of data matters may be found on our Web site: <www.georgetown.edu/research/gucdc/eval.html>



WEB-BASED SOURCES

For organizations, agencies, and resources related to the development and implementation of performance outcomes, indicators, and measures for behavioral health care.

Accreditation Commission of Rehabilitation Facilities

(CARF)—Non-profit organization gives accreditation to behavioral health, rehabilitation and community service programs. Offers professional training. A member of the Accreditation Organization Workgroup.

<http://www.carf.org>

American College of Mental Health Administration

(ACMHA)—National organization for mental health and substance abuse administrators, consumers, and family leaders. Review A Proposed Set of Performance Indicators and Measures for Behavioral Health prepared by the American College of Mental Health Administration and the Accreditation Organization Workgroup.

<http://www.acmha.org>

American Managed Behavioral Healthcare Association

(AMBHA)—Contracting with health maintenance organizations or other health care delivery systems, both public and private, AMBHA member organizations offer individualized care management, specialty networks, a continuum of care, and quality management programs.

<http://www.ambha.org>

Council on Accreditation for Children and Family

Services, Inc. (COA)—COA is an international, independent not-for-profit organization. COA accredits approximately 1400 programs that provide child welfare services. A member of the Accreditation Organization Workgroup.

<http://www.coanet.org>

Council on Quality and Leadership in Support of Persons With Disabilities

—A member of the Accreditation Organization Workgroup and contributor to “A Proposed Set of Performance Indicators and Measures for Behavioral Health” in collaboration with The American College of Mental Health Administration (no website—see resource above for ACMHA)

CSAP Core Measures Initiative

—CSAP Core Measures Initiative goals, objectives, and CMI notebook with CMI Viewer, which walks the reader through the selection, downloading and/or printing of the appropriate measure. Go to <http://www.preventiondds.org> and search for Core Measures Initiative.

Decision Support 2000+—An integrated set of mental health data standards and an information infrastructure designed to help all stakeholders answer key questions and make critical decisions that will improve quality of care.

<http://mhsip.org/ds2000/newindex.htm>

FACCT—The Foundation for Accountability—FACCT is a not-for-profit organization that helps consumers understand health care quality, compare health plan and provider performance, and make quality-based decisions.

<http://www.facct.org>

HIPAA—Health Insurance Portability and Accountability Act of 1996—A new focus from MHSIP providing information on the Act and its implications for behavioral health services.

<http://www.mhsip.org/hipaa/index.html>

Institute of Medicine (IOM)—Chronicles the IOM charter, recently released reports, members, program activities, and links to related resources.

<http://www.iom.edu/>

Joint Commission on Accreditation of Healthcare Organizations (JCAHO)

—A nationwide, not-for-profit health care accreditation agency in support of performance improvement in health care organizations. A member of the Accreditation Organization Workgroup.

<http://www.jcaho.org>

Mental Health Statistics Improvement Program (MHSIP)

—For answers to who is providing the best services at the best price, who needs services, what the best treatments are for different kinds of problems.

<http://www.mhsip.org>

National Committee for Quality Assurance (NCQA)

—National data on childhood immunizations, health care screening, access to health care, and percentage of mental health patients in hospitals. A member of the Accreditation Organization Workgroup.

<http://www.ncqa.org>

Mental Health: Culture, Race, and Ethnicity—A Supplement to Mental Health: A Report of the Surgeon General.

U.S. Department of Health and Human Services. [DHHS], 2000. <http://www.sg.gov/library/mentalhealth/cre/default.asp>

HHS Policy for Improving Race and Ethnicity Data.

U.S. Department of Health and Human Services. Office of Information Resources Management. <http://www.os.dhhs.gov/oirm/infocollect/inclusion.html>

Unequal Treatment: Confronting Racial and Ethnic

Disparities in Health Care March 2002. Brian D. Smedley, Adrienne Y. Stith, and Alan R. Nelson, Editors, Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care, Board on Health Sciences Policy. Institute of Medicine.

<http://www.nap.edu/books/030908265X/html/>

Outcomes in a System of Care continued from page 1

A common theme throughout this issue of Data Matters is the need to identify meaningful outcomes for different stakeholders and audiences and provide the tools to understand and use the outcome data. For each data user, whether a consumer or family member, an advocacy organization, a clinician, a supervisor or administrator, a board member, or a state level administrator policy maker or researcher, a guiding question is: "How can outcome data help me do my job better?" ♦

For more information on State level efforts to identify and measure outcomes, see the National Scan on Children's Services Evaluation <www.georgetown.edu/research/gucdc/eval.html#scan>

Ohio Takes A Statewide Approach continued from page 6

produces two reports for the case manager or clinician—a Red Flag Report that lists all the items which individuals have scored as particularly problematic, and a Strengths Report which lists all those areas in which an individual is doing well and that would be areas to build upon.

In the summer of 2000, the Department offered \$3 million in Outcomes Incentive Grants to local systems for start-up costs. Forty-two local systems (including 192

provider agencies) took the grants, which required a one-year implementation process that would result in outcomes data flowing to the state by September of 2001. In addition, trainings were held and an Outcomes Tool Kit was developed for each provider agency which included training materials for introducing the Outcomes System as well as for teaching case managers and supervisors how to use the data in treatment planning and monitoring. Forty-one local systems are now flowing data to the state, and the Department is continuing to bolster data use at the local level, but in addition has turned its attention to data use at the aggregate level for quality improvement at the provider agency and local system level. Another statewide workgroup has been convened that is advising the Department about the kinds of statewide comparative benchmarking reports that would be the most useful at the local level, and it is anticipated that reports will begin to be produced in the late summer. ♦

Contact persons for the Ohio Mental Health Consumer Outcomes System are Dee Roth, MA, (614/466-8651) and Leslie Brower, PhD, (614/752-9704) Co-Chairs of the Outcomes Initiative. Extensive information—including background, implementation, and resource materials—is available on the Outcomes System's web site: <www.mh.state.oh.us/initiatives/outcomes/outcomes.html>

Data Matters



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