

Introduction

States are being asked to create a comprehensive system of care for children with special health care needs (CSHCN) and their families as outlined in Healthy People 2010 and supported by the President’s New Freedom and “No Child Left Behind” initiatives. This system of care is comprised of six core goals:

1. Families partner in decision making at all levels and are satisfied with their services;
2. Children receive coordinated, ongoing comprehensive care within a medical home;
3. Families have adequate insurance to pay for needed services;
4. Children are screened early and continuously for special health care needs;
5. Community-based service systems will be organized so families can use them easily;
6. Youth receive services to transition successfully to all aspects of adult life.

States must not only have the capacity to implement these goals, but they also need to be able to measure and monitor their progress to assist in their continuous quality improvement efforts. To assist in this process, the Early Intervention Research Institute conducted a project from 1998-2003 funded by the Division of Services for Children with Special Health Needs (DSCSHN) entitled “*Measuring and Monitoring Community-Based Systems of Care*” (M&M). M&M staff worked in partnership with state CSHCN leaders and key stakeholders to understand their current capacity

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to monitor the six CSHCN core goals and to initiate data-based decision making to guide their implementation efforts. Over the past 5 years, M&M has collaborated with 10 states: Arizona, Colorado, Florida, Hawaii, Iowa, Ohio, Oregon, South Carolina, Utah, and Vermont. These states demonstrated strong commitment, time, and effort without receiving any financial compensation for their participation. In addition, measurement strategies have been disseminated to other states via presentations at AMCHP, short-term consultations, and other MCH-related activities.

This summary highlights the accomplishments of the M&M project staff as well as the accomplishments of our partner states. Recommendations to support future state efforts are offered following the accomplishments.

Accomplishments

M&M staff established a nine-step “*Assessment to Action*” process to support states in their efforts to achieve the six aforementioned measures of a system of care. This process emphasizes the importance of building state capacity necessary for data-based decision making. M&M staff facilitated a series of meetings and activities in each state to support the following accomplishments of the participating M&M states.

Step 1: Getting Organized

In each M&M state, a Participatory Action Research (PAR) team was formed comprised of stakeholders from the broader system of care. M&M staff encouraged each state interagency team to bring together missing



representatives who previously had little direct communication with the state's CSHCN program. These teams typically consisted of representatives from CSHCN, MCH/public health, Medicaid, Family Voices, education, mental health, vocational rehabilitation, developmental disabilities, early intervention, as well as physicians and other health providers. State teams clearly benefited from strong CSHCN program leadership to initiate the momentum for M&M activities and to maintain focus on the M&M workscope.

Step 2: Establishing the Vision

In the initial phase of the M&M project, a unified "vision" was created via development of a series of indicators to represent "necessary ingredients" of a system of care. The purpose of the indicators was to provide guidance to states in *implementing* a system of care as well as *measuring and monitoring* their achievements. Therefore, the indicators were designed to go beyond what currently could be reported in order to capture the *vision* of what the system should look like. The development of indicators became the initial focal point of the state PAR team activities. Indicator development was accomplished through the following collaborative process.

1. The M&M staff reviewed the literature to identify potential indicators with face validity for measuring each of the six core goals.
2. Indicators were selected based on consensus achieved by a broad consortium of stakeholders from six states including MCH and CSHCN directors, family representatives, education, vocational rehabilitation, early intervention, Medicaid, pediatricians, and other private providers.
3. These indicators were verified by DSCSHN staff and validated by other HP 2010 efforts (e.g., the Medical Home Initiative, National Survey for CSHCN). Contact M&M project staff for a list of these indicators.

The M&M project helped to establish a shared vision in each state by facilitating a review of its state priorities identified in the Title V block grants, needs assessments, and other state plans to determine which of the six core goals warranted particular emphasis. This helped to ensure that states viewed M&M as a *support for integrating their existing vision* rather than as a separate or parallel effort.

One of the M&M project's greatest accomplishments was to ensure "buy-in" from state agencies that were unsure about their role in achieving the six CSHCN goals. For example, M&M staff worked to convey the importance of the participation of vocational rehabilitation by emphasizing how measuring the six goals could benefit that program (e.g., demonstrating the need for vocational services could help them in requests for funding; creating a medical home effort for young adults with special needs can ensure achieving health status to be successfully employed). One of the greatest challenges, particularly in times of fiscal constraints, continues to be ensuring that stakeholders maintain a shared vision as something that will benefit—and not detract—from individual programs.

Step 3: Taking Stock of Current Measurement Capabilities

M&M staff facilitated the activities of state data subcommittees to identify existing data sources both within the CSHCN program and from the other key stakeholders. All the M&M states identified new data sources not previously considered, such as the Consumer Assessment of Health Plans (CAHPS) data, school system transition data, Head Start data regarding screening and medical home, and survey data from the Developmental Disabilities program.

The breadth of the data sources identified depended on the "buy-in" from needed partners and their willingness to share information. For example, state Medicaid programs typically collect a great deal of data that can

be used to measure the extent to which CSHCN have a medical home, adequate coverage for needed services, and screening. Some states found it a challenge to break through bureaucratic barriers to obtain data from other departments or programs; as a result, these states were limited to identifying data sources primarily from within the CSHCN program or within the broader MCH program.

Step 4: Obtain Data Results to Guide Future Decision Making

Data subcommittees from all the M&M states obtained actual data results from a wide array of sources both within and outside of the CSHCN program. Most of the data results were survey data from sources such as CSHCN client surveys, randomized household health surveys, CAHPS, Family Voices “Your Voice Counts,” etc. Data related to transition came from the Department of Education and Medical Home project surveys. Data results are now available from the National Survey on CSHCN as well. The 16 of the 28 indicators that states were typically able to measure via interagency data coordination are listed below.

1.0 Families partner and are satisfied.

- 1.1: % families reporting satisfaction with the quality of primary care, obtaining referrals, needed services, coordination among providers.
- 1.2: % of parents who report satisfaction with their level of involvement in setting concerns/priorities about their child’s care.

2.0 Medical home

- 2.1: % with a regular source of primary medical care through a primary care provider.
- 2.2: % whose regular source of primary medical care communicates in a way that is clear and understandable to the family.

- 2.3: % of parents whose regular source of primary medical care identifies, discusses, and addresses the comprehensive needs of their child and family.

- 2.5: % of parents who receive referrals and assistance from the regular source of primary medical care in accessing needed services.

3.0 Adequate insurance

- 3.1: % with insurance to cover the costs of needed services.
- 3.2: Amount of out-of-pocket costs paid by families.
- 3.3: % who can choose providers of their choice.
- 3.4: % whose insurance provides timely approval for needed care, overall parent satisfaction, clear information about coverage, resources, and complaint procedures.

4.0 Screening

- 4.1: % of infants whose mothers began prenatal screening in the first trimester of pregnancy.
- 4.2: % of infants and families being monitored for special health care needs and developmental delays.

5.0 Services are organized

- 5.2: % of parents who report that they are able to access comprehensive services for their child and family.
- 5.3: % of parents who have specialty care available in their region of the state.

6.0 Transition to adulthood

- 6.1: % of youth who have a transition plan by age 14 (typically available for children in Special Education only).
- 6.2: % of youth whose regular source of primary medical care facilitates the transition from pediatric to adult providers.

In general, states were less prepared to supply data for 12 additional indicators. There are various reasons why these indicators are a challenge. First, these tended to be indicators based on multiple data sources (i.e., metabolic screening, newborn hearing screening, Early Intervention developmental screening, EPSDT); or second, they reflected the presence of greater levels of interagency collaboration within the current system, particularly at local levels (i.e., participation at state and local levels; interagency enrollment/eligibility process). Indicators that have been a greater challenge to measure are:

1.0 Families partner and are satisfied

- 1.3: % of parents who know steps to take when they are not satisfied with services.
- 1.4: % of parents who are supported financially for their involvement in state and local activities.
- 1.5: % of parents who report that they are effective partners in policymaking at state and local levels.

2.0 Medical Home

- 2.4: % whose regular source of primary medical care ensures age-appropriate well-child checks, including vision, hearing, developmental, oral health, behavioral/mental health, newborn screening, immunizations.

4.0 Screening

- 4.3: % of children receiving age-appropriate well-child checks, including vision, hearing, developmental, oral health, behavioral/mental health, metabolic, and EPSDT.
- 4.4: % of children receiving needed follow-up due to failed screening (most states are able to monitor follow up of newborn hearing screening).

5.0 Services Organized

- 5.1: % of parents who have a coordinated service plan that involves *all* providers and a *lead service coordinator* who communicates with the family.
- 5.4: The degree to which the state service system has an enrollment/eligibility process that links families and their medical home with a wide variety of public and private services and resources.
- 5.5: The number of private/public partnerships to provide community-based, comprehensive medical services for CSHCN (data sharing, contracts, Memorandums of Agreements).

6.0 Transition to adulthood

- 6.3: % of adult health care providers who are prepared to serve youth with SHCN.
- 6.4: % of youth who report satisfaction with the information and training they received to make informed decisions about their health care and other services.
- 6.5: % of youth who received desired services and supports by age 21, including post-secondary education, employment, health insurance, transportation, housing, personal care attendant, SSI, SSA-related work incentives (e.g., PASS, 1619 a & b).

Monitoring the broader CSHCN population: States continue to be challenged in the ability to monitor progress on using the broad definition of CSHCN: “those children 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 to children generally.” Issues affecting state capacity to monitor and measure the progress for this broad CSHCN population are listed below.

- Household samples of CSHCN provide the most accurate approximation of the children who fit the broad definition of CSHCN. Some states have collected data on a randomized sample of children fitting this definition based on state-designed health surveys. The National Survey of CSHCN provides a common denominator for across-state comparisons, although it will not provide information on *every* child with a special health need.
- Some states are able to monitor progress for the broadly defined CSHCN population served by Medicaid, but not necessarily for those with private insurance or on SCHIP.
- The relatively small sample size from some of these surveys makes it difficult to determine the needs of particular populations, such as children with asthma, cerebral palsy, Down syndrome, etc.
- CSHCN from diverse cultures tend to be underrepresented, making it difficult to use survey data to judge the needs of all children.
- Some states are able to report on children served through their CSHCN clinics only.
- Some data sources were available one time only (i.e., Family Voices “Your Voice Counts” survey, or Utah’s Child Health Survey).

This variability in samples makes it more challenging to compare data results across states. Many states are relying on the National Survey of CSHCN to provide the common metric for reporting and to conduct state-by-state comparisons. However, data on smaller populations can provide useful information to guide State’s program improvement efforts. Therefore, M&M staff encourage states to consider all their available data

to complement the information to be obtained from the National Survey of CSHCN.

Step 5: Share Results to Ensure Data-Guided Continuous Quality Improvement (CQI) Decisions

State PAR teams used the data gathered to answer the following questions.

- What do the data reveal about the strengths of our system of care?
- What do the data tell us about the challenges families face?
- What do the data reveal about changes needed to the system of care?

For almost all of the M&M states, this was the first time that key stakeholders shared actual data results with one another. As stated earlier, the data results were found to be of great interest to the PAR teams and helped reinforce the “unified vision.” At times agencies were cautious about sharing their program-level data with those outside of their program, perhaps due to concerns that it might be misinterpreted. States with data integration or data warehousing projects appeared to have greater interagency collaboration for overcoming these kinds of barriers.

Step 6: Developing an Action Plan for Improving the Service System

This step involved developing an action plan for *enhancing measurement and monitoring* capacity and *developing implementation strategies* for improving the system of care. States made great accomplishments in strengthening their measurement capacity by creating new tools, enhancing existing tools, or enhancing the use of data from their stakeholders.

Examples of strategies states used to measure and monitor the M&M indicators include:

1. *Statewide Surveys*

- CSHCN program family satisfaction surveys (i.e., South Carolina, Ohio).
- State-specific child health surveys, (i.e., Utah, Iowa, Arizona, Hawaii).
- National surveys, such as the National Survey of CSHCN; Medical Expenditure Panel Survey (all states)
- Nationally standardized state-level surveys, such as CAHPS, PRAMS (i.e., Utah, Vermont, Colorado, Oregon, Hawaii)
- Issue-specific interagency surveys such as transition, medical home focus (i.e., South Carolina, Ohio, Utah).

2. *Data Warehousing*

One of the M&M states (South Carolina) established the capacity to combine data from multiple departments (e.g., Health, Education, Medicaid, Mental Health, and Vocational Rehabilitation) for a particular point in time. This method can be used to obtain a complementary estimate of the number of CSHCN as well as track outcomes such as percent of children with a primary care provider.

3. *Data Integration*

Utah, Colorado, and Oregon are developing integrated data systems that will be used by multiple programs. Currently, their data integration efforts will allow them to track early and continuous screening by linking birth records, newborn hearing screening, early intervention screening, and metabolic screening.

4. *Proportional Population Estimates (PPE)*

Vermont is exploring the process of determining the overlap between CSHCN populations served by Vocational Rehabilitation and Medicaid. Using PPE analysis procedures, an estimate can be determined of the percent of CSHCN who have received assistance from specific supports through vocational rehabilitation to successfully transition to adult life.

Examples of strategies that states use to drive program implementation include:

- Using the M&M indicators as the basis for developing a CQI process, guiding the identification of their community-level priorities and implementation plans (Colorado, South Carolina).
- Incorporating measurement into state action plans (Arizona, Utah, Oregon).
- Using the M&M indicators to guide other grant activities such as the Medical Home (Vermont, Utah, Ohio).

The M&M project had the opportunity to work collaboratively with the majority of the partnering states through Step 6. The complete “*Assessment of Action*” process involves working through the following additional steps. M&M hopes to continue to offer support to states as they work to the “action” or implementation phase of achieving a system of care for CSHCN.

Step 7: Disseminate the Action Plan to Stakeholders at the Community and Family Levels

This step is an interagency effort that is critical for educating the broader base of stakeholders at the community level in order to build a foundation for developing a *community-based system of care*. In

preparation for disseminating data results, state PAR teams should answer the following questions.

- Who comprises the audience for receipt of the information?
- What are the information needs of the audience?
- What do you expect the audience to do with the information?
- What is the message you want to deliver?
- How will you deliver the information to your audience?

Step 8: Implement the Action Plan for Improving the Service System

The identification of discrete, operationalized procedures; setting due dates; and ensuring necessary funding and staff support are examples of the planning that must occur.

Step 9: Evaluate and Improve the Measurement and Action Plan Process

States must establish a process for monitoring their progress via repeated measures. This monitoring will allow for data-based decision making to revise the action plan as needed.

Future Directions and Recommendations

Based on our experience in partnering with 10 states on the M&M project, it is evident that many states are committed to implementing data-based decision making to guide their achievement of Healthy People 2010. States recognize the value of collecting data to identify the needs of children and families, to drive implementation efforts, and to document achievements. Although this process continues to be a challenge, particularly in time of fiscal constraints, states also recognize the importance of interagency collaboration to measure and monitor their progress in achieving a system of care. Through the incorporation of the six goals into the Title V Block Grant, states now have a strong mechanism to guide their focus on measuring and monitoring their efforts toward achieving a system of care for the children and youth with special health care needs.

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Healthy People 2010 Website

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