

How are these indicators being used?

The six pilot states are using the indicators to guide their measurement and monitoring efforts. The indicators are useful in designing surveys and program quality improvement tools, providing states with an opportunity to measure their achievements. Additionally, the indicators are being used in data warehouses and data integration efforts. The indicators help states to fine tune their reporting of the performance measures in the Title V Block Grant. For example, states are now able to obtain more comprehensive data to measure the extent to which children have a medical home. Some states have used the outcomes and indicators to develop state-specific performance measures that are then incorporated into their Title V Block Grant.

What can states do to enhance their own measurement capacity?

The six states in the M&M Project demonstrate the value of applying a Participatory Action approach to guide their measurement efforts. Participatory Action is a way of doing business whereby decisions are made by a team of 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 have established such teams are better poised to develop data collection methods that are practical as well as family centered. State-specific parent advocacy groups, such as Parent to Parent of Vermont and Family Voices, are active partners in driving CSHCN policies, practices, and measurement. Direct service providers, such as pediatricians and public health nurses, provide valuable insights into how to gather data in meaningful ways and ensure its accuracy. Organizations, such as state chapters of the American Academy of Pediatrics and March of Dimes, are also invested in achieving CSHCN outcomes, and their involvement as participants strengthens measurement efforts.

A Participatory Action approach provides the opportunity for various public and private programs to dialogue regarding common goals and priorities found across programs. This can lead to the development of new strategies for working together. Examples of collaborative measurement strategies can be found in three inserts that accompany this document.

This project was supported by funds from the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, Division of Services for Children with Special Health Needs, (grant no. 6HOMC00064-01) to the Early Intervention Research Institute at Utah State University, Logan, UT

M&M Project Contacts

Richard N. Roberts
Principal investigator
Early Intervention Research Institute
Utah State University
(435) 797-1172 • richr@cpd2.usu.edu

Diane D. Behl
Co-principal investigator
Early Intervention Research Institute
Utah State University,
(435) 797-1224 • behld@cpd2.usu.edu.

For electronic copies, visit our website: eiri.usu.edu/projects.htm

M&M State Contacts

AZ: Merrill Krenitz,
Planning and Evaluation
Specialist, Office of Children
with Special Health Care
Needs, (602) 542-2528
mkrenit@hs.state.az.us

OH: James Bryant
Acting Director, Maternal
and Child Health
(614) 466-1549
jbryant@gw.odh.state.oh.us

OR: Cathy Renken
Assistant Director, Services
for Children with Special
Health Needs
(503) 494-6961
renkenc@ohsu.edu

SC: Linda Price
Director, Children's
Rehabilitative Services
(803) 898-0789
priced@columb60.dhec.state.sc.us

UT: Vera Francis Tait
Bureau Director,
Children with Special Health
Care Needs
(801) 584-8239
ftait@doh.state.ut.us

VT: Carol Hassler,
Director, Children's Special
Health Needs
(802) 863-7338
chassle@vdh.state.vt.us

DSCSHN Federal Contact

Diana Denboba
Integrated Services Branch, Division of Services for Children
with Special Health Needs (DSCSHN)
(301) 443-2370 • DDenboba@hrsa.gov

HP 2010 Website

www.mchb.hrsa.gov/html/expresshom.htm

Reference

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. (2001) Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Dept. of Health and Human Services.

All states are being asked to create a comprehensive system of care for children with special health care needs and their families as outlined in the federal 10-year action plan: *All Aboard the 2010 Express*. This plan is the culmination of several parallel activities sponsored by the Division of Services for Children with Special Health Needs (DSCSHN) of the Maternal and Child Health Bureau (MCHB). The plan represents an exciting partnership among public, private, and family sectors at the federal, state, and local levels all working together to create a system of care for children and families. To create this system, six performance outcomes must be achieved. *All Aboard the 2010 Express* delineates recommended policies and practices to be implemented to achieve the six outcomes:

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.

How is CSHCN defined?

Children with Special Health Care Needs are defined as those 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. It is estimated that 16-18% of the population of children ages birth to 21 fit within this definition.

Why is measurement of the six outcomes important?

In addition to implementing recommended strategies delineated in *All Aboard the 2010 Express*, state Title V programs will be responsible for working with community, state, and federal partners to measure and monitor progress in achieving CSHCN outcomes. The collection of data about each of the six outcomes is necessary for several purposes—identifying the children with special health care needs, reporting outcome results, and guiding state efforts to ensure a comprehensive coordinated system of care. 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. Data-based decision making allows states to make wise choices in how to allocate funds by monitoring the extent to which activities achieve the desired results. In sum, 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.

What is the M&M Project?

The M&M Project is funded by DSCSHN and is a collaborative endeavor of the Early Intervention Research Institute 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 the CSHCN outcomes and to help them enhance their capacity through expanded measurement and monitoring efforts. A critical step for reaching this end was to develop indicators to facilitate outcome measurement.

How were the M&M indicators created?

Teams from each of the participating states comprised of parents, administrators, service providers, and data personnel were formed to develop the indicators. These teams met with M&M staff several times to craft a series of indicators that represented both their state's current capacity to collect data as well as their new strategies to achieve the six outcomes for children and their families by 2010. An extensive consensus-building process involved representatives from all six states and narrowed the list to 4-5 indicators per outcome. DSCSHN staff provided input that was incorporated into the list of indicators.

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.

1. % of families of CSHCN reporting satisfaction with the quality of: regular source of primary care, obtaining referrals and appointments for needed services, coordination among primary care, specialty care, overall services.
2. % of parents of CSHCN who report satisfaction with their level of involvement/input in setting concerns and priorities to make decisions about their child's care plan.
3. % of parents of CSHCN who report knowing the steps to take when they are not satisfied with the services their child/family receives.
4. # of parents of CSHCN who are supported financially for their involvement in state and local activities.
5. # of parents of CSHCN who report that they are effective partners in policymaking at the state and local levels.

Outcome #2:

All children with special health care needs will receive coordinated ongoing comprehensive care within a medical home.

1. % of CSHCN with a regular source of primary medical care through a primary care provider.
2. % of CSHCN whose regular source of primary medical care communicates in a way that is clear and understandable to the family.
3. % of parents whose regular source of primary medical care identifies, discusses, and addresses the comprehensive needs of their child and family.
4. % of CSHCN whose regular source of primary medical care coordinates age-appropriate well-child checks, including: vision, hearing, developmental, behavioral/mental health, oral health, newborn screening, immunizations.
5. % of parents of CSHCN who receive referrals and assistance from their regular source of primary medical care in accessing needed/desired services.

Outcome #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.

1. % of CSHCN with insurance that covers costs of needed services, including: mental health, dental care, age-appropriate well-child checks, durable medical equipment, ancillary services, non-durable medical supplies, care coordination, prescriptions, specialty care, related therapies (e.g., PT, OT, speech/language, audiology), in-home nursing.
2. Amount of out-of-pocket costs paid by families of CSHCN, including costs of: mental health, dental care, age-appropriate well-child checks, durable medical equipment, ancillary services, non-durable medical supplies, respite care, transportation, care coordination, prescriptions, specialty care, related therapies (e.g., PT, OT, speech/language, audiology), in-home nursing, home modifications, car/van modifications.
3. % of CSHCN who can choose the providers of their choice.
4. % of CSHCN whose insurance provides: timely approval for needed care, overall parental satisfaction, clear information about coverage, resources, complaint procedures for providers and parents.

Outcome #4:

All children will be screened early and continuously for special health care needs.

1. % of infants whose mothers began prenatal screening in the first trimester of pregnancy (e.g., substance abuse, genetics).
2. % of infants and families being monitored for special health care needs and developmental delays.
3. % of children receiving age-appropriate well-child checks including: vision, hearing, developmental, behavioral, mental health, oral health, metabolic, EPSDT (if implemented in state).
4. % of children receiving needed follow-up due to failed screening: vision, hearing, developmental, behavioral, mental health, oral health, metabolic.

Outcome #5:

Community-based service systems will be organized so families can use them easily.

1. % of parents of CSHCN who have a coordinated service plan that involves all providers and a lead service coordinator who communicates with the family.
2. % of parents of CSHCN who report that they are able to access comprehensive services for their child and family.
3. % of parents of CSHCN who have specialty care available in their region of the state.
4. The degree to which the state service system has an enrollment/eligibility process that links families of CSHCN and their medical home with a wide variety of public and private services and resources.
5. # of private/public partnerships to provide community-based, comprehensive medical services for CSHCN (e.g., data sharing, contracts, MOAs).

Outcome #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.

1. % of youth with SHCN who have a transition plan by age 14 that includes input from education, health, vocational rehabilitation, mental health, or other appropriate agencies, which addresses transportation, housing, independent living, and necessary accommodation.
2. % of youth with SHCN whose regular source of primary medical care facilitates the transition from pediatric to adult providers.
3. % of adult health care providers who are prepared to serve youth with SHCN.
4. % of youth who report satisfaction with the information and training they received to make informed decisions about their health care and other services.
5. % of youth with SHCN 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).