



The Connecticut Medical Home Initiative for Children & Youth with Special Health Care Needs

Measuring and Monitoring Community-Based Systems of Care



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**:

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.

- % 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.
- % 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.
- % of parents of CSHCN who report knowing the steps to take when they are not satisfied with the services their child/family receives.
- # of parents of CSHCN who are supported financially for their involvement in state and local activities.
- # 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.

- % of CSHCN with a regular source of primary medical care through a primary care provider.
- % of CSHCN whose regular source of primary medical care communicates in a way that is clear and understandable to the family.
- % of parents whose regular source of primary medical care identifies, discusses, and addresses the comprehensive needs of their child and family.
- % 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.
- % 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.

- % 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.
- 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.
- % of CSHCN who can choose the providers of their choice.
- % of CSHCN whose insurance provides: timely approval for needed care, overall parental satisfaction, clear information about coverage, resources, complaint procedures for providers and parents.

Measuring and Monitoring Community-Based Systems of Care, cont.

Outcome #4: All children will be screened early and continuously for special health care needs.

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

- % of parents of CSHCN who have a coordinated service plan that involves all providers and a lead service coordinator who communicates with the family.
- % of parents of CSHCN who report that they are able to access comprehensive services for their child and family.
- % of parents of CSHCN who have specialty care available in their region of the state.
- 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.
- # 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.

- % 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.
- % of youth with SHCN whose regular source of primary medical care facilitates the transition from pediatric to adult providers.
- % of adult health care providers who are prepared to serve youth with SHCN.
- % of youth who report satisfaction with the information and training they received to make informed decisions about their health care and other services.
- % 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).



Keeping Connecticut Healthy