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# Medical Home Status for Children with Special Health Care Needs in Massachusetts: Background Brief

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## Executive Summary



*Prepared for the  
Massachusetts Consortium  
for CSHCN by:*

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This is an executive summary of a background brief entitled, *Medical Home Status for Children with Special Health Care Needs in Massachusetts*. Members of the **Massachusetts Consortium for Children with Special Health Care Needs (CSHCN)** have gathered and summarized information from a range of sources to describe the current baseline of awareness, interest and resources for building a medical home capacity for CSHCN in Massachusetts. The document was developed as background material in preparation for the March 14 and May 2, 2002, meetings of the Massachusetts Consortium for CSHCN. The focus of the agenda for these meetings was on assessing the current status of promoting the medical home concept in Massachusetts, and exploring strategies for achieving one of the national goals contained in the 10-year Action Plan to Achieve Community-based Service Systems for Children & Youth with Special Health Care Needs and Their Families (U.S. Dept. of Health & Human Services, 2001): *All children with special health care needs will receive coordinated, ongoing, comprehensive care within a medical home.*

**This document is a product of the Massachusetts Consortium for Children with Special Health Care Needs, developed with the support of the following members:**

- Baystate Pediatric Group, Baystate Medical Center Children's Hospital
- Boston Medical Center, Department of Pediatrics
- Brandeis University, Heller School
- Bridgewater Goddard Park Medical Associates
- Center for Families, Children's Hospital Boston
- Department of Maternal and Child Health, Boston University School of Public Health
- Federation for Children with Special Needs
- Harvard Vanguard Medical Associates
- Health & Disability Working Group, Boston University
- Health Care for All
- Massachusetts Department of Mental Health
- Massachusetts Department of Mental Retardation
- Massachusetts Department of Public Health
- Massachusetts Division of Medical Assistance
- Massachusetts Family Advisor Initiative
- Massachusetts Family TIES
- Massachusetts Family Voices
- Massachusetts Respite Coalition
- MassGeneral Hospital for Children, Center for Child and Adolescent Health Policy
- MASSTART (Massachusetts Technology Assistance Resource Team)
- Nashaway Pediatrics, Sterling, MA
- Neighborhood Health Plan
- New England SERVE
- Shriners Burns Hospital - Boston
- Tufts University Center for Children

## What is a *Medical Home*?

A medical home is not a building, house or hospital, but rather an approach to providing health care services in a high-quality and cost-effective manner. Children and their families who have a medical home receive the care that they need from a pediatrician or other physician whom they trust. Pediatric health care professionals and parents act as partners in a medical home to identify and access all the medical and non-medical services needed to help children and their families achieve their maximum potential. The American Academy of Pediatrics believes the medical care of infants, children and adolescents should be:

- *accessible,*
- *continuous,*
- *comprehensive,*
- *family-centered,*
- *coordinated,*
- *compassionate, and*
- *culturally effective.*

(American Academy of Pediatrics, 2002)

These characteristics define the *medical home*.

It is important to realize that *medical home* is both a *concept* and a set of principles, and as such is difficult to define and measure. However, there is growing endorsement of the medical home concept including statements by the American Academy of Pediatrics and the American Academy of Family Physicians. The *2010 Action Plan for Children with Special Health Care Needs (CSHCN)* is a ten-year plan endorsed and promoted by the Maternal & Child Health Bureau in the Health Resources and Services Administration of the U. S. Department of Health and Human Services, and endorsed by the American Academy of Pediatrics, Family Voices, the March of Dimes and over 50 other national organizations.

The Action Plan includes the specific goal of assuring a *medical home* for all children with special health care needs by 2010. Parallel efforts to promote the concept of *medical home* as well as the necessary work of developing operational measures for *medical home* will be proceeding together over the next decade at both the state and national levels. In this context, children with special health care needs are defined as: *those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.*

Healthy People 2010 offers a set of health goals for the nation and reflects current health planning at the national level. The nation's health plan recognizes that the key to improving care for CSHCN lies in a systems approach to organizing and delivering that care. Objective 16-23 of Healthy People 2010 is to "increase the proportion of states and territories that have *service systems* for children with special health care needs." Achieving this objective has been further defined by the federal Maternal and Child Health Bureau as accomplishing six core outcomes (U.S. Dept. of Health & Human Services, 2001):

1. Families of CSHCN will participate in decision making at all levels and will be satisfied with the services they receive.
2. All CSHCN will receive regular ongoing, comprehensive care within a medical home.

3. All families of CSHCN 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 (YSHCN) will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work and independence.

This Executive Summary presents the highlights of a full report entitled, *Medical Home Status for Children with Special Health Care Needs in Massachusetts: Background Brief*. The Background Brief has been prepared for the Massachusetts Consortium for CSHCN as a first step in assessing the readiness, capacity and early signs of implementation of *medical homes* for CSHCN in the Commonwealth.

## **Massachusetts Leadership Activities Help to Build Medical Home Capacity**

The medical home concept has grown out of work at the national level addressing the adequacy of primary care for all children, and especially the opportunities available within community based primary care settings for improving the quality of systems of care for CSHCN. Massachusetts has been a leader in refining the medical home concept. A number of pilot projects in the Commonwealth have demonstrated effective elements of the medical home model, working with small groups of CSHCN or sub-populations. In addition, a number of new initiatives are currently engaged in evaluating specific strategies for supporting a system of medical homes.

Nine Massachusetts projects that have contributed to building capacity for medical home development are briefly described in the full document. These projects include initiatives established by public agencies such as the Massachusetts Departments of Public Health, Social Services, Mental Health, Education, Youth Services and the Division of Medical Assistance, as well as private sector groups such as Children's Hospital, Neighborhood Health Plan, New England SERVE, Shriner's Hospital for Children, Nashaway Pediatrics and the Massachusetts Chapter of the American Academy of Pediatrics.

## **Primary Care Provider Interest & Satisfaction in Caring for CSHCN**

Primary care physicians in Massachusetts and across the country have demonstrated an ongoing interest in enhancing the quality and comprehensiveness of primary care for CSHCN. They are also expressing an increased level of concern about their ability to provide appropriate care for this population without additional resources and supports. A number of surveys of pediatric primary care providers conducted at the state, regional and national levels have been designed to assess provider satisfaction, and identify the challenges involved in providing quality primary care for CSHCN. Relevant findings from four such surveys are highlighted in the full document. Areas consistently identified by primary care physicians caring for CSHCN as opportunities for improvement include: *adequacy of time to meet with child and family, access to specialized clinical information, communication with specialty care providers, access to consultation, and supports to assist in managing psychological or emotional needs of child and family.*

Despite these constraints in the primary care setting, many pediatric providers express a willingness and capacity to increase the number of CSHCN in their practices if additional supports were to become available, including access to care coordination and additional information on community resources for families.

## **Family Awareness & Family Satisfaction with Primary Care for CSHCN**

A number of surveys of families caring for CSHCN conducted at the state, regional and national levels have included questions related to primary care, family support and care coordination - all attributes of medical home. Sample findings from four such surveys are cited in the full document. These include: 1) the Massachusetts Department of Public Health/Division of Medical Assistance Managed Care Enhancement Project that reported on survey findings from 321 families in 1996; 2) the National *Your Voice Counts Survey* conducted by Family Voices and Brandeis University that surveyed 103 Massachusetts families in 1998-99; 3) the New England SERVE *Shared Responsibilities* Project that reported on 542 families caring for children enrolled in Neighborhood Health Plan in 2000; and 4) the MassHealth Managed Care Member Survey, which used the CAHPS survey instrument and included 2,319 child member surveys, of which 600 were identified as CSHCN. These survey results highlight the need for improved coordination of care in both hospital discharge planning and community based settings, and emphasize the challenges that families face in achieving joint decision-making and planning with their child's medical providers, and in obtaining mental health services, respite care and information about their child's medical condition. A summary of the results of nine parent leaders' use of the Medical Home Index to assess their own child's primary care setting is also provided.

## **National Resources for Developing & Measuring *Medical Home* Capacity**

As Massachusetts strives to meet the 2010 goal of assuring that every CSHCN receives care within a medical home, national programs and projects will provide useful resources and materials. Four national resources and their websites and contact information are cited and briefly described in the full document. These include:

1. *American Academy of Pediatrics: National Center of Medical Home Initiatives for Children with Special Needs* <http://www.medicalhomeinfo.org/>
2. *National CSHCN Survey: Maternal and Child Health Bureau (MCHB)* <http://www.cdc.gov/nchs/slait.htm>
3. *Medical Home Index: Developed by the Center for Medical Home Improvement (CMHI) at Children's Hospital at Dartmouth Hitchcock Medical Center in New Hampshire* <http://www.medicalhomeimprovement.org/>
4. *Monitoring and Measuring Project (M&M Project) at the Early Intervention Research Institute at Utah State University* <http://www.eiri.usu.edu/>