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



*Prepared for the
Massachusetts Consortium
for CSHCN by:*

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This background brief presents an overview of *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.*

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- 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
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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 achieve their maximum potential. The American Academy of Pediatrics believes that the medical care of infants, children and adolescents should be:

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

These characteristics define the *medical home*.
(*American Academy of Pediatrics, 2002*)

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 developed 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 offer 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 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.

Reflections on Medical Home... from a generalist primary care provider:

Providing excellent community-based primary care for children who may have special health care needs (CSHCN) is a challenge that is emerging only now for generalist physicians to recognize, confront and meet. Many Massachusetts physicians in the 1940's and 1950's supported the statewide perception and policy that institutional care for children with serious disabilities and specialized needs was most appropriate. Consequently, community physicians rarely encountered children with significant disabilities in their offices. The 1960's and 1970's saw a fundamental policy shift away from institutional care to community based care, and medical advances of the 70's and 80's brought new technologies and treatments for critically ill newborns and chronic illnesses that resulted in remarkable improvements in survival.

Implementation of a new community based focus in the 1980's included marked expansion of family services to support CSHCN in their homes and a gradual growth of community based group homes and other supports for adults with disabilities.

Traditional pediatric primary care was, however, designed for the 80% of children who do not have special health care needs, with a focus on preventive services and acute illness management through a single service unit: the provider-patient encounter. The typical medical student or resident experience of an ambulatory office encounter with a child with special health care needs was an exam room surprisingly filled with complexity, people and problems, and remarkable particularly for interfering with the otherwise comfortable, controlled, "well-oiled machine" patient flow and office atmosphere. The prescribed encounters and available resources did not fit CSHCN, and the needs themselves were unpredictable and, often, unimaginable.

For the practicing generalist in the 1990's, while the challenge might have been inviting and the parent involvement refreshing, the "cost" in office disruption combined with the increasing squeeze on office resources associated with managed care contracting made it hard to embrace caring for CSHCN. What has become clear, in retrospect, was the fundamental mismatch between the way typical generalist offices organized and delivered care for the vast patient majority, and the needs of CSHCN. It is also clear from the emerging patient safety literature that working harder will not help. The complexity of care required for CSHCN whether medical, educational, social, economic, or spiritual requires re-evaluating the system in which care is rendered not greater effort within the "old" system.

Medical home is, fundamentally, an approach to providing health care services in a high-quality and cost-effective manner in an environment where health care professionals and parents act as partners to identify and access all the medical and non-medical services needed to help CSHCN and their families achieve their maximum potential. It is characterized by the seven "Cs": *care which is accessible, family-centered, comprehensive, continuous, coordinated, compassionate, culturally competent*. Many generalist physicians will, after a glance at this description, conclude, "I already do that" in my office. The devil is, however, in the details but, unlike making sausage or legislation, generalist physicians are enlightened by gaining an awareness of

what goes into building and providing a medical home. With medical home, the opportunity to benefit patients by revising the way care is organized and delivered is in the details. As physicians have the opportunity to explore various resources, participate in training and review relevant materials, they will be seeking answers to these basic questions: Where did the concept of *medical home* come from? What is it? Why is it necessary? How does it fit with my current practice? It is in the answer to these questions that physicians will come to appreciate the power inherent in medical home to improve both the quality of care and health outcomes for CSHCN, their families and our communities.

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. The process of operationalizing the medical home concept began in earnest in 1992 with a specific policy statement by the American Academy of Pediatrics (*Dickens MD, Green JL, Kohrt AE, 1992*) followed by an investment in research, demonstration and training programs throughout the country. These efforts have examined a number of issues highlighting the complexity of providing comprehensive and coordinated care for this population of children and families. 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 or activities that have contributed to building capacity for medical home development are briefly described. Although several of these activities were not specifically designed to demonstrate the medical home concept, they have helped advance the process of defining medical home by demonstrating a component, and in so doing have set the groundwork for a statewide focus on medical homes for CSHCN.

1. ***DPH-DMA Managed Care Enhancement Project***. In 1994, as enrollment into Medicaid managed care began in Massachusetts, DPH and DMA teamed up to develop a joint quality improvement project aimed at ensuring that managed care would work well for CSHCN and their families. With support from the federal MCHB, the agencies carried out a needs assessment survey of parents and primary care providers of CSHCN enrolled in MassHealth managed care. The needs assessment was followed by several pilot interventions to address the needs identified, including the assignment of a Special Care Coordinator in primary care offices to enhance PCP capacity to carry out effective care coordination. The project was completed in 1999 with the development of a Resource Manual for families of CSHCN, and an evaluation of the Special Care Coordinator pilot intervention.

2. ***Pediatric Alliance for Coordinated Care (PACC)***. The Pediatric Alliance for Coordinated Care is a medical home demonstration project initiated in 1997 and coordinated through the Division of General Pediatrics at Children's Hospital. Operating in 6 community-based pediatric sites in Massachusetts, and serving 154 CSHCN, the PACC project has been conducting a study of a coordinated approach to primary care that includes specialized supports and training for physicians, nurses and families, and the impact of this package of medical home services on health outcomes, service utilization and family and provider satisfaction. In 2000, PACC published a physician operations manual for implementing a medical home. (*Silva TJ, Sofis LA, Palfrey JS, 2000*)
3. ***Massachusetts Mental Health Services Program for Youth (MHSPY)***. The MHSPY program began as a Robert Wood Johnson Foundation supported project in 1997, as one of 12 state replication sites designed to test the original MHSPY model for children with serious emotional disturbance, in a managed care setting. MHSPY serves 30 children in the Cambridge-Somerville area who are Medicaid eligible and who also receive services from one other state agency or school, offering an integrated, community based alternative to children who are at risk for out of home placement. Unique features of the program include being linked to a primary care provider, integration of physical health, mental health and substance abuse treatment services, and a care planning process that is family-focused and community-based. Families participate in the design of an individualized plan of care including access to non-traditional services and supports in the home, school and community. These services are supported with blended funds from the Departments of Mental Health (DMH), Social Services (DSS), Youth Services (DYS) and Education (DOE) and the Division of Medical Assistance (DMA).
4. ***Special Kids/Special Care***. This program is a medical pilot project initiated in 2000 to serve children in foster care with special health care needs who require complex medical management and skilled nursing care, or skilled assessment or monitoring related to an unstable medical condition. The program is a collaborative project of DSS, DMA and Neighborhood Health Plan. *Special Kids/Special Care* offers a nurse practitioner focused model of managed care for special populations in the context of an active primary care setting. Components of the model include care coordination, collaboration between foster families and providers, facilitated access to network providers and updated and detailed comprehensive information on patients and their needs. This program currently serves 40 children in the custody of DSS in Massachusetts.
5. ***Massachusetts Medical Home Initiative***. The Massachusetts Medical Home Initiative was established in January 2001 when Massachusetts was invited by the national American Academy of Pediatrics (AAP) to participate in the first National Medical Home Conference. The Massachusetts Medical Home Steering Committee operates as a subcommittee of the Massachusetts Consortium for CSHCN, and provides a link for Massachusetts to the resources of the *National Center of Medical Homes Initiatives for Children with Special Needs* at the AAP. Massachusetts has been selected as one of four states to receive a small grant to support work to develop medical home initiatives in the Commonwealth, and to serve as a mentoring team for another state's Medical Home Initiative.

6. ***Providing a Medical Home: The Cost of Care Coordination in a Community-based General Pediatric Practice.*** With the support of the federal MCHB, in 2000, pediatricians at Nashaway Pediatrics, a group practice within UMASS Memorial Community Medical Group, conducted a study to determine the costs of providing care coordination services to CSHCN in a general pediatric practice. Using a standardized coding format, over 95 study days, the practice measured the time spent by all staff in performing activities relating to coordinating comprehensive care for CSHCN. Services for which reimbursement could be received were not included in the analysis. During the study time frame, 774 encounters were logged representing care coordination activities for 444 separate patients. Using a system for classification of clinical complexity, the most complex patients constituted 11% of the population of CSHCN, but were the subject of 25% of the care coordination encounters. 51% of the encounters were attributed to non-medical care coordination needs including managing referrals to sub-specialists, education program consultations and consultations on psychosocial issues. Based on national salary and benefit benchmark data, the cost of providing care for CSHCN in this practice of four FTE physicians and one FTE nurse practitioner is between \$27,000 (25th percentile) and \$42,000 (75th percentile). (*Antonelli RC, 2001*)
7. ***DPH Care Coordination Project.*** In 2001, The Massachusetts Department of Public Health began a new initiative to collaborate with primary care practices in the state to enhance care coordination for CSHCN. This pilot project supports a nurse educator to assist practices across the state to link with existing DPH resources as well as community-based services for CSHCN and their families. In addition, primary care practices are collaborating in a demonstration and evaluation of office based care coordination. Seven (7) primary care pediatric practices have been selected as partnership sites and now have a DPH funded care coordinator working directly in their practice. The program is expected to expand to 20 sites by 2003.
8. ***Massachusetts Chapter of the AAP (MCAAP).*** The MCAAP has formally endorsed the principles of the Medical Home Policy statement of the AAP as well as the 2010 Action Plan for CSHCN and took the leadership in bringing the National Medical Home training program to Massachusetts in November 2001. The MCAAP is now working to develop a mentoring and support strategy for assisting pediatricians to expand their capacity to provide Medical Homes to CSHCN.
9. ***“Every Child Deserves a Medical Home” Shriner’s Hospital/AAP National Medical Home Training Program.*** In November 2001, Massachusetts hosted the National Medical Home Training program, a one-day curriculum-based conference that offered specific training on the common elements of medical home, and showcased practice models, policies and procedures for providing comprehensive, coordinated, collaborative care. A total of 158 people participated including physicians, allied health providers, and families of CSHCN. A second national medical home training program is scheduled to be held in Springfield, Massachusetts in 2003.

Statewide Physician Capacity

The Massachusetts Board of Registration in Medicine licenses 31,813 physicians, of which 22,642 report their business address within the Commonwealth. Current registrations include:

- 1,955 identified as Board certified in Pediatrics
- 2,001 identified as primary specialty Pediatrics
- 1,401 identified as Pediatricians- no specialty
- 1,175 identified as Family Practice specialty

The MCAAP reports 1,725 physician members. The Massachusetts Academy of Family Physicians has 704 active members, and 84 life members. Information on geographic distribution is not readily available at this time.

Primary Care Provider Interest & Satisfaction in Caring for CSHCN

One indicator of system readiness to develop and implement medical homes for CSHCN is physician interest in current medical home initiatives throughout the Commonwealth. The medical home training program held in Boston in November, 2001, attracted 158 participants, of which 63 were physicians practicing in Massachusetts. The recent DPH care coordination project received twelve letters of intent, and sixteen actual applications from pediatric primary care sites interested in collaborating with the Department in demonstrating an office based care coordination model for CSHCN. Two new grant supported activities that are designed to improve child and family health within a medical home model of care have engaged the interest of three additional pediatric practices in central Massachusetts. An attempt to provide an unduplicated count of physicians demonstrating interest in medical home related initiatives estimates the number as 75-80.

What do we know about pediatric primary care providers' satisfaction with their ability to provide comprehensive and appropriate primary care to CSHCN?

A number of surveys of pediatric primary care providers conducted at the state, regional and national levels have included questions that reflect on elements of the medical home. These surveys 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 briefly highlighted below.

1. ***Assessing the Quality of Managed Care for CSHCN: Results of a Regional Survey of 253 Pediatric Primary Care Providers in 4 New England States, 1995-1996.*** Two hundred fifty-three (253) providers in four New England states (CT, RI, NH, VT) caring for CSHCN responded to this regional survey and reported moderate satisfaction with their ability to provide appropriate primary care for CSHCN. Slightly more than half (53%) reported that they were somewhat satisfied with *adequacy of time to meet with child and family*; 56% reported being somewhat satisfied with their *access to specialized clinical information*, and 54% with their *communication with specialty care providers*. The lowest level of satisfaction reported within the primary care domain was with their *access to consultation and supports to assist in managing psychological or emotional needs of child and family*, with 53% responding they were not satisfied. Seven additional items clustered in the domain of Care Coordination demonstrate similarly moderate levels of satisfaction among pediatric primary care providers with their ability to appropriately coordinate care for CSHCN. (*New England SERVE, 1997*)

2. ***DPH-DMA Managed Care Enhancement Project: Survey of 194 Primary Care Providers; 2 Focus Groups, 1996.*** As background for the Managed Care Enhancement Project, the Department of Public Health surveyed pediatric primary care providers across the Commonwealth and conducted focus groups. Results from 194 completed surveys indicated that only 57% of providers were very satisfied with their relationship with parents of CSHCN. Providers noted that time constraints, poor communication, uncooperative families, and parent stress were associated with their dissatisfaction. Additionally, only 45% of providers surveyed were very satisfied with their relationship with specialists to whom they refer CSHCN. Factors associated with dissatisfaction with relationships with specialty care providers included lack of communication, inaccessibility, lack of teamwork and cooperation and difficulty in coordination of care. (*Mass. DPH, 1996*)
3. ***Shared Responsibilities Project: Survey Results from 172 Pediatric Primary Care Providers Affiliated with Neighborhood Health Plan (NHP), 2000.*** As part of a quality improvement project for CSHCN conducted in collaboration with New England SERVE, NHP surveyed all of its pediatric primary care providers in 2000 and met with a 46% response rate. This included responses from 172 pediatric providers at 31 primary care sites across the state. The survey was designed to tap provider experiences caring for CSHCN in managed care, and included questions about both their ability and satisfaction with their own capacity to deliver appropriate primary care to CSHCN. Providers reported that they do not feel they have enough time to meet with CSHCN and their families. One in ten say they *never have enough time*, while an additional 35% say they *rarely have enough time*, and 41% say they *sometimes have enough time* to meet with CSHCN and their families. Despite constraints in the primary care setting, 64% of the providers in this survey expressed a willingness and capacity to increase the number of CSHCN in their practices: 13% said they were interested in caring for more CSHCN regardless of additional supports being available; 51% stated an interest in increasing the number of CSHCN in their practice if they were to receive additional supports such as training, additional time for office visits and care coordination, changes in productivity standards, and information on available community resources. (*NHP and New England SERVE, 2000*)
4. ***National AAP Periodic Survey #44, Summer 2000.*** A national survey by the AAP of its members was conducted in 2000 to determine the extent to which pediatricians are providing medical homes to CSHCN. Pediatricians reported that 27% of children in their practices met the MCHB definition of CSHCN; 94% reported providing 24-hour/7 days week telephone access to their patients; 69% provided emergency care on evenings and weekends. 60% report providing Saturday morning appointments; 43% weekday evening appointment times. While a large majority (71%) of pediatricians felt they always provided care coordination within the context of a medical home, only 24% always contacted schools, 41% always discussed non-medical needs, and only 19% always provided an appointment to discuss the results of sub-specialist consultations. (*AAP, 2000*)

Family Awareness & Family Satisfaction with Primary Care for CSHCN

What do we know about family satisfaction with the care their child receives from their primary care provider and his/her staff?

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 five such surveys are highlighted below.

1. ***DPH-DMA Managed Care Enhancement Project: 4 Focus Groups and 321 Family Surveys, 1996.*** Focus groups and family survey findings from this project indicated that coordination of health care with school services was a problem for families. Survey results indicated that coordination of care in hospital discharge planning, home care and school health services needed improvement. The results of the survey also showed that families have had difficulty obtaining support in a number of areas, such as mental health counseling (for their child, themselves, other family members), family to family support, respite, coordinating medical appointments, and school and Early Intervention enrollment. (*Mass. DPH, 1996*)
2. ***Family Voices: Your Voice Counts Survey - 103 Massachusetts Families, 1998-99.*** Between March 1998 and April 1999, Family Voices and Brandeis University conducted a national survey of the health care experiences of families of CSHCN. Families were randomly selected from state Title V programs serving CSHCN and Family Voices mailing lists. In Massachusetts, 103 families completed the Your Voice Counts survey. The descriptive data below provides some indication of the level of Medical Home services described by these families of CSHCN.
 - 97% of children surveyed have a primary care provider (PCP)
 - 74% report that the PCP has the necessary skills and experience
 - 83% report that their satisfaction with their child's most important doctor including the family in decision-making and planning is "excellent" or "good"
 - 86% report that their satisfaction with the child's most important doctor respecting culture, ethnic identity and religion is "excellent" or "good"
 - 78% report that their satisfaction with their child's most important doctor communicating with other providers is "excellent" or "good"(*Family Voices, 2000*)
3. ***Shared Responsibilities Project: 542 Family Surveys, 2000.*** As part of a quality improvement project for CSHCN, Neighborhood Health Plan (NHP) surveyed families caring for children identified as *likely to be CSHCN*, and asked about their experiences with primary care, specialty care, care coordination, mental health, therapeutic services, emergency and inpatient care, medical supplies and equipment, and member services. Results of 542 family surveys (309 English/233 Spanish) in the area of Primary Care indicate that nearly three-quarters of families report having enough time to meet with their child's primary care provider (PCP), while only half of families indicated that they get help from their child's PCP in addition to office visits; 44% of families reported that their PCP and specialty care providers talk regularly; 37% of those surveyed do not know if their child's providers communicate regularly. Thirty seven percent of families reported that they receive help coordinating their child's care from their primary care site; 45% reported that they did not get any help with care coordination. Families identified the need for additional assistance in coordinating health care and educational services. Additional care coordination needs

identified by families included help getting needed services such as transportation, adaptive equipment, disposable medical supplies and home nursing. (*NHP and New England SERVE 2000*)

4. ***MassHealth Managed Care Member Survey 2000-2001.*** The 2000-2001 DMA Child Member Survey of children enrolled in one of 5 Medicaid managed care plans (Boston Medical Center Health Plan, Fallon, NHP, Network Health, and PCC Plan) used the Consumer Assessment of Health Plans Study (CAHPS) survey instrument, including a new series of questions that were under review by the National Committee on Quality Assurance (NCQA) as possible supplements to the CAHPS core instrument. These supplemental items were designed to better capture the experiences of CSHCN, and included a battery of items to identify CSHCN, and a series of questions concerning medical decision-making, family centered care, coordination of care, and communication. The DMA Child Member Survey was distributed to 600 children from each of the contracted HMOs, and an additional 1,800 children drawn from the PCC Plan, for a total sample of 4,200; 2,319 Child Member Surveys were completed.

Results were analyzed for the subset of approximately 600 children identified as CSHCN (across all five plans). Sample results listed below show the median responses to specific items within each of three composite scores, *Information from Doctors*, *Making Decisions*, and *Getting Special Care* that may be considered to contribute to medical home. It should be noted that these items are written to allow families to report on a mix of experiences from primary care, specialty care and any other health care providers who help them by responding to questions, providing information about their child's care, are involved in health care decision-making, or assist families in accessing special services.

Information from Doctors:

- 57% of CSHCN families report that their child's doctors or other health care providers: *always* made it easy to discuss questions or concerns (n 593)
- 52% report that they *always* got the specific information they needed (n 598)

Making Decisions:

- 60% report their child's doctors or other health care providers *always* involved them in decisions about their child's care as much as they wanted (n 463)

Getting Special Care:

- 74% report it was *not a problem* to get special medical equipment (n 131)
- 72% report it was *not a problem* to get special therapy for their child (n 165)
- 70% report it was *not a problem* to get treatment or counseling for their child (n 266)

Results comparing experiences of children who did and did not have special health care needs showed no significant differences in composite scores for these two groups.

(*Stringfellow VL, Fowler FJ, 2001*)

5. ***Summary of Nine Massachusetts Parent Leaders' use of Medical Home Index.*** In January 2002, nine parent leaders in Massachusetts, all familiar with the medical home concept, were asked to use the Medical Home Index (see description below) to assess their child's primary care setting as a medical home. Only four of the nine parents reported that they can always get the health care that their child needs through their child's primary care provider's practice. Three parents indicated that their PCP always asks for parent knowledge and expertise as a caregiver; two parents reported that their PCP never asks for such participation.

While four parents indicated that their provider never asks how the child's condition affects the family, two parents said that their provider always asks and three said that their provider sometimes or often does. All nine of the parents reported that their child's primary care provider had never developed a written care plan for their children.

Health Plan Awareness of Challenges Ensuring Quality Care for CSHCN

Massachusetts Family Advisor Initiative

In 2000, the *Massachusetts Family Advisor Initiative* recruited, trained and supported 14 parents of CSHCN to conduct in-depth interviews at nine managed care plans throughout the Commonwealth. This project attempted to increase the number of parents of CSHCN in the state interested and involved in conversations about managed care. These interviews became part of a national project that has completed a total of 41 interviews with managed care organizations across the country over the past three years. Interviews with health plans in Massachusetts highlighted that plans are aware of a number of challenges in ensuring quality care and attempting to improve their capacity to serve CSHCN. While the specific concept and label *medical home* may not be familiar to all, there is evidence in the interviews that health plan leaders are aware of the fragmentation of care, the coverage and financing across multiple payers, and the challenges faced in identifying CSHCN among their membership. All plans interviewed in Massachusetts reported that they permit primary care providers to arrange for standing referrals for specialty care for up to one year. Five of the nine plans permit families to make a special request that a pediatric sub-specialist be their child's primary care provider. Most plans do not use any special payment methods to compensate primary care providers or specialists for the additional time spent caring for CSHCN. (*Family Voices and New England SERVE, 2001*)

Strategies for Implementing *Medical Home*

MCHB Action Steps

As part of the MCHB 2010 Action Plan, three specific action steps to achieving a medical home for all CSHCN are defined. The steps and some of the recommended strategies to achieving them are summarized below.

1. *Standardize the core elements of the medical home*
 - Revise AAP definition of medical home
 - Establish outcome based rationale for the definitive elements of a medical home by developing consensus statements
 - Demonstrate the efficacy and feasibility of the medical home
 - Incorporate evidence-based definition of medical home in the training of health and health-related professionals
2. *Promote the medical home approach*
 - Provide analysis of medical home data
 - Incorporate medical home concepts into interdisciplinary training
 - Develop, describe and disseminate good models of coordination between primary and specialty care providers
 - Assist other professionals who work with children to assume their collaborative roles in assuring a medical home for all CSHCN

3. *Achieve universal access to medical homes*

- Identify a statewide focal point to provide leadership in the development of medical homes
- Convene a consortium of stakeholders
- Expand efforts to link all children to medical homes
- Review reimbursement for key elements of medical home

Pediatric Alliance for Coordinated Care (PACC)

The Pediatric Alliance for Coordinated Care (PACC) has been demonstrating a medical home model in 6 pediatric sites in Massachusetts, now serving 154 CSHCN. The medical home model proposed by the PACC program adds three key features to routine primary care:

- The services of a designated pediatric nurse practitioner (PNP) employed by each site to provide home visits to assess the child's situation, care coordination, and development of an individual health plan for each child.
- Family access to a trained parent volunteer who is familiar with the local community because of personal experiences to provide personal support, resource guidance and special events and activities for children and parents.
- Modifications of office routines to do a better job of incorporating the CSHCN population including strategies for managing office visits, office training and guidelines to treat families more compassionately and efficiently and specialized on-call procedures to aid physician partners less familiar with the care of CSHCN.

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, their websites and contact information are cited and briefly described below.

1. ***American Academy of Pediatrics: National Center of Medical Home Initiatives for Children with Special Needs.*** The national office of the American Academy of Pediatrics (AAP) operates a National Center of Medical Home Initiatives for Children with Special Needs under a cooperative agreement between the AAP and the federal Maternal & Child Health Bureau (MCHB). The mission of the Center is to work in cooperation with federal agencies to ensure that CSHCN have access to a medical home. The Center provides educational and advocacy materials, guidelines for care, evaluation tools and a national contact network. The Center developed and now coordinates the planning and delivery of the ***Every Child Deserves a Medical Home Training Program***, offers technical assistance to states and maintains a website for dissemination of resource materials. [The American Academy of Pediatrics, 141 Northwest Point Boulevard, Elk Grove Village, IL 60007-1098; Phone: (847) 434-4000; Fax: (847) 434-8000; Web site: <http://www.medicalhomeinfo.org/>]
2. ***National CSHCN Survey: Maternal and Child Health Bureau (MCHB).*** The federal MCHB in partnership with the national Center for Health Statistics has developed a new survey that will provide uniform national and state data on prevalence and impact of special needs among children. Data collection began in October 2000, and continued for 12 months. Summary reports for each state are expected in Summer 2002. Each state will receive information based on telephone surveys conducted with family members of 750 CSHCN. Data collected will include demographics, health and functional status, health insurance

coverage and adequacy, public program participation, access to care, utilization of health care services, care coordination, satisfaction with care and impact of the special need on the family. Many items will contribute to providing baseline assessment data on “medical homeness.” [National Center for Health Statistics, Division for Health Interview Statistics, 6525 Belcrest Road - Room 850, Hyattsville, MD, 20782-2003, Attention: SLAITS; E-mail: slaits@cdc.gov; Fax: (301) 458-4035; Web site: www.cdc.gov/nchs/slaits.htm]

3. ***Medical Home Index: Center for Medical Home Improvement (CMHI)***. The *Medical Home Index* is a measurement tool reflecting the necessary and sufficient elements of a pediatric primary care medical home, using observable, objective and verifiable indicators. The Index is constructed to help pediatric practices conduct a self-assessment and includes both a Provider version and a Family version of the Index. These tools have been developed by researchers at the Hood Center for Children and Families, at Children’s Hospital at Dartmouth Hitchcock Medical Center in New Hampshire. The Medical Home Index is designed to assess the “medical homeness” of a health care practice or office setting to determine how well it provides comprehensive family-centered care for CSHCN. The degree to which a practice achieves “medical homeness” can be measured across six domains that encompass the activities that bring the medical home to life:

- organizational capacity,
- chronic condition management,
- care coordination,
- community outreach,
- data management, and
- quality improvement.

(Cooley WC, McAllister JW, 2002)

The CMHI has also produced a 200-page medical home improvement kit, *Building a Medical Home: Improvement Strategies in Primary Care for Children with Special Health Care Needs*, which describes a medical home in detail. [Center for Medical Home Improvement, Hood Center for Children & Families, Children’s Hospital at Dartmouth-Hitchcock Medical Center, One Medical Center Drive, Lebanon, NH, 03756-1479; Phone: (603) 653-1480; Fax: (603) 653-1479; Web site: www.medicalhomeimprovement.org]

4. ***Monitoring and Measuring Project (M&M Project)***. The Monitoring and Measuring Project at the Early Intervention Research Institute at Utah State University has developed a preliminary set of indicators to measure each of the MCHB Action Plan goals. The 5 indicators for Goal #2 are:

- Percent of CSHCN with a regular source of primary medical care through a primary care provider.
- Percent of CSHCN whose regular source of care communicates in a way that is clear and understandable to the family.
- Percent of parents whose regular source of primary medical care identifies, discusses and addresses the comprehensive needs of their child and family.
- Percent 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.
- Percent of parents of CSHCN who receive referrals and assistance from their regular source of primary medical care in accessing needed/desired services. [Early Intervention Research Institute, Center for Persons with Disabilities, Utah State University, Logan, UT, 84322-6580; Phone: (435) 797-1172 or (800) 887-1699; Fax: (435) 797-2019; Web site:

<http://eiri.usu.edu/MandM/default.htm>]

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