

# Improvement in the Family-Centered Medical Home Enhances Outcomes for Children and Youth With Special Healthcare Needs

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**Abstract:** Family-centered, coordinated, comprehensive, and culturally competent care for children and youth with special healthcare needs is a national priority. Access to a primary care medical home is a US Maternal and Child Health Bureau performance measure. Most primary care practices lack methods by which to partner with families and improve care. Gaps remain in the number of children with access to a high-quality medical home. The Medical Home Index and Medical Home Family Index and Survey resulting from 10 pilot practices reveal improvements in practice capacity and subsequently in child and family outcomes. **Key words:** *children and youth with special healthcare needs, family-centered, medical home, outcomes, primary care, utilization of healthcare services*

**S**PECIAL HEALTHCARE NEEDS affect the daily lives of more than 12 million American children, youth, and their families (Newacheck et al., 1998; Van Dyck et al., 2008). Children and youth with special healthcare needs (CYSHCN) have 3 times as many hospital bed days and school absences as do other children. Eighteen percent of their families reported dissatisfaction with 1 or more aspects of their usual source of healthcare, with

13% reporting unmet healthcare needs in the previous year (Newacheck et al., 2000). Five percent of all children require complex care involving multiple community agencies and multiple healthcare providers (Perrin et al., 1993). While encompassing a minority of US children, this population accounts for well over half of the national expenditure on pediatric healthcare (Newacheck et al. 1998). Children and youth with complex health conditions may be cared for by multiple doctors or healthcare teams, yet they lack a single locus of care planning and care coordination. Care easily becomes fragmented and often drifts toward busy specialists who may be unable to focus on comprehensive healthcare needs extending beyond their area of specialization.

The quality of healthcare services and the efficiency with which they are provided are crucial patient, professional, and public health issues for the 21st century. The Institute of Medicine has identified the fragmentation of healthcare for individuals with chronic medical conditions at all ages as a national concern (Committee on Quality of Health Care in America, Institute of Medicine,

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2000). In a Commonwealth Fund survey, 90% of healthcare opinion leaders identified strengthening primary care and encouraging care coordination as their top 2 recommendations for improving the nation's healthcare system (Shea et al., 2008).

The primary care medical home occupies a central role in healthcare reform for all children, youth, and adults (Backer, 2007; Schoenbaum & Abrams, 2007). The *medical home* is defined by the American Academy of Pediatrics as a model for delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective (American Academy of Pediatrics Medical Home Initiatives for Children With Special Needs Project Advisory Committee, 2004). New Hampshire's Center for Medical Home Improvement (CMHI) explains the medical home as a community-based primary care setting that provides and coordinates high-quality, planned, family-centered health promotion, acute illness care, and chronic condition management (Cooley et al., 2008). Professionals, policy makers, and families have long regarded the medical home model as a fundamental necessity for all children and of critical importance to children/youth with special healthcare needs (Cooley, 2007). In the pediatric medical home model, physician-led interdisciplinary healthcare teams manage and facilitate all aspects of care and do so in a culturally effective partnership with families. Healthcare teams in the medical home work to know the children, youth, and families who make up the population for which they care, and the families know and identify the professionals in their medical home as consistent partners. Families of children with special healthcare needs seek a medical home that (1) offers a collaborative family-centered team approach, (2) develops a written summary of critical care information, and (3) has a developed process to integrate and coordinate care across multiple services (Kelly et al., 2002). Pediatric primary care is ideally positioned to be such a locus of care and coordination (Cooley & McAllister, 2004). Primary healthcare providers have a long-standing re-

lationship with their patients. They have the potential for communication both vertically among levels of the continuum of healthcare and horizontally across agencies and supports in the local community (Cooley, 2004).

There is a small but growing body of evidence demonstrating the efficacy of the primary care medical home. Demonstrated benefits include improved individual health, reduced overall costs of care, improved health of select populations, and increased satisfaction among patients and providers (Starfield & Shi, 2004). Both Starfield and a 2007 Commonwealth Fund report discuss the reduction in health disparities among socioeconomic groups for individuals with steady access to a primary care medical home (Beal et al., 2006; Commonwealth Fund Commission on a High Performance Health System, 2006). However, a gap remains between the ideal concept of a medical home and the current realities of primary care quality, access, and affordability. Under current healthcare reimbursement arrangements, *quantity* rather than *quality* determines payment (Bodenheimer, 2006). Daily productivity pressure allows few opportunities for primary care teams to transform themselves into fully implemented medical homes. Therefore, demonstrations that the medical home improves overall access, quality, and efficiency remain sparse. During well child visits as well as during typical short-term illness episodes, pediatricians and family physicians struggle to address the demands and necessary management of children with chronic conditions. This dynamic is well described in the Institute of Medicine report "Crossing the Quality Chasm: A New Health Care System for the 21st Century," which states that "the current care systems cannot do the job. Trying harder will not work. Changing systems of care will" (Committee on Quality of Health Care in America, Institute of Medicine, 2000). The US Maternal and Child Health Bureau funded 8 medical home implementation projects between 2001 and 2004, 1 of which was awarded to New Hampshire's CMHI. CMHI recruited 10 primary care practices (rural, suburban, urban) to participate in the implementation of a series of

medical home improvements specifically targeting the care and support in a medical home for CYSHCN. Improvements involved the identification of CYSHCN and their enrollment in a registry (paper or electronic), the development of a practice-based care coordination role to enhance the healthcare team's ability to offer planned care and use written care plans, and the provision of patient education designed to help families build their confidence and skills in the care of their children and in the navigation of the healthcare system (McAllister et al., 2007). The aims for medical home improvement targeted enhanced clinical, functional, satisfaction, and cost outcomes. These included child and family outcomes and improved primary care practice functioning involving elevated staff satisfaction. This article provides a description of a multiyear pediatric medical home demonstration project, the improvement methodology used, and the practice and family outcomes achieved.

## METHODS

The mission of the CMHI is to promote high-quality primary care in a medical home and to secure health policy changes critical to the future of primary care. CMHI uses a quality improvement model to help primary care offices build a stronger medical home. The process used in this demonstration involved planned changes in practice structures and processes, which resulted in demonstrable improvement in value to consumers, providers, and payers. Quality improvement efforts involved those individuals who were most familiar with the processes of care that were targeted for change. This meant not only clinicians and staff but also the consumers of care (families/caregivers). Therefore, parents and caregivers of CYSHCN became equal and critical partners of the medical home improvement team. The core team included a lead physician, a care coordinator (nurse or social worker), and 2 parents of children with special healthcare needs who met regularly to consider what needed improvement, whom the improvement was meant to benefit, and

how the team would know (or measure) whether improvement occurred. CMHI's approach with each practice is purposefully flexible. Self-direction at the level of the practice team often leads to more creative individualized and focused efforts with varied enhanced outcomes.

Ten practice teams were selected to participate; each team was known to its peers for having a special interest in the care of CYSHCN. They were engaged in 3 years of medical home improvement. The geographical location of the practices spread from southeastern New Hampshire across to northwestern Vermont. All physician team leaders were pediatricians; 2 of whom practice in a community health center model. Five practices are part of a hospital-owned network and the other 3 are each independently owned small group practices of 2 to 4 providers.

Improvements tested and implemented by the teams relate to family-centered quality care processes and office efficiencies for CYSHCN. Three phases describe the implementation. Phase I included an orientation to the improvement process and to the establishment of baseline measurements. Phase II included initial and periodic collaborative learning conferences involving all participating practice teams. These sessions were interspersed among regular ongoing improvement team meetings or "action periods." Phase III involved practice and family review of improvement outcomes using pre- and postmeasures, a celebration of accomplishments, and plans for sustainability and future development.

The medical home improvement teams established their baseline measurements, identified an aim or focus for change, and decided on small steps or "tests of change" that could be quickly applied and evaluated. The results led to further refinements and new changes of increasing complexity. This process ensured that the team was not overwhelmed by a task too large or complicated or not misled in a direction of change that did not improve care. Quality improvement experts refer to this process as the Plan, Do, Study, Act or PDSA cycle in which the team plans a change, tries it

out, studies the effects, and then acts on its observations to inform the next planning step (Langley et al., 1996).

Improvements in individual office settings were fostered on a larger scale through a collaborative learning process in which improvements in one office setting were then shared with other medical home practices. This process of shared learning was established through conferences (learning sessions), conference calls, electronic communications, and the involvement of an improvement facilitator or coach who carried ideas from one practice site to another. All sites shared the overarching aim of improving their medical home in a manner pleasing to their patients and families, while maintaining the financial viability of the practice. Practices were each provided with enough financial support to help them develop their capacity to begin to provide practice-based care coordination (about 4 h/wk) (McAllister et al., 2007).

The Center for Medical Home Improvement used the Medical Home Index (MHI) and the Medical Home Family Index and Survey (MHFIS) to enable practices to establish their own individual baseline data and document improvement (Cooley et al., 2003). The MHI was also used to measure outcomes across the learning collaborative or demonstration project. The MHI is a nationally validated tool that organizes 25 medical home indicators under 6 domains: (1) organizational capacity, (2) chronic condition management, (3) care coordination, (4) community outreach, (5) data management, and (6) quality improvement. Teams used the MHI as a baseline (year 1), midpoint (year 2), and final (year 3) measure. The MHFIS provides a consumer report on practice performance, on the family experience of care, and detailed clinical, functional, satisfaction, and cost outcomes of child and family. The MHFIS included the family report of 25 different practice performance and quality care measures. Additional questions in the MHFIS focus on a child's functional health status; healthcare utilization; and parental/caregiver level of stress, worry, burden of illness, and ability to coordinate care.

Following 30 months of facilitated quality improvement efforts, CMHI evaluated results from both the practice perspective and the perspective of the children, youth, and families who regularly use these medical homes. For the third and final measure, the practiced physician/team again completed the MHI. Families reported on practice performance and on their own experiences of care by completing the (post) MHFIS, marking their second report. Data for children, families, and the practice provided a descriptive analysis for each practice and a composite picture for the improvement cohort, or learning collaborative, collectively. These measures reveal practice and family strengths, highlight weaknesses, and guide future improvement.

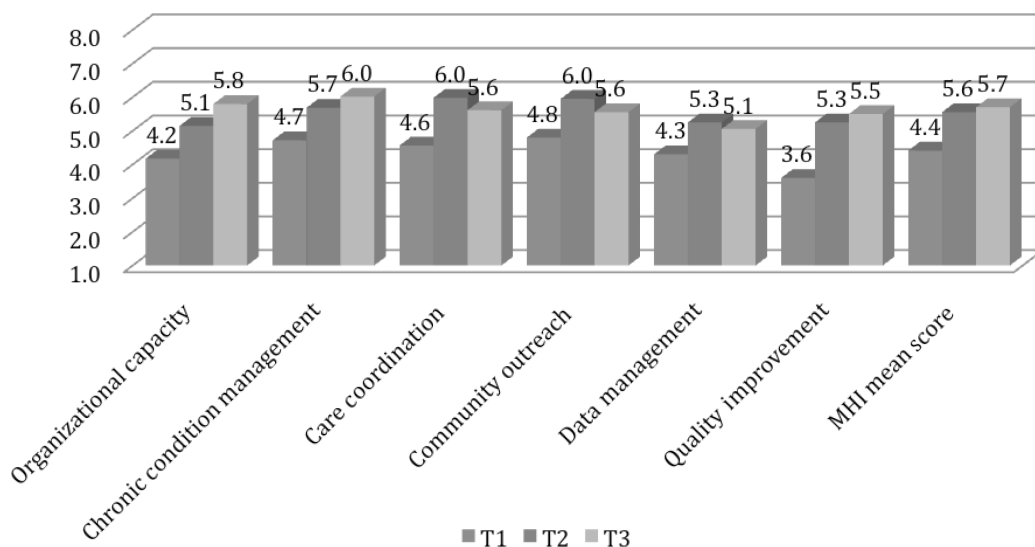
## RESULTS

Over the course of 3 years, 10 practices demonstrated a 30% increase overall from their baseline MHI scores (Fig 1) ( $n = 10$  practices). As you can see from Figure 1, results were demonstrated after 2 years and changes sustained over the subsequent third year.

### THE MHI—TESTS OF SIGNIFICANCE

One-sample  $t$  tests were conducted with the differences in means of the MHI mean domain and total scores between time points 1 and 3 to determine whether the changes were significantly different from no change (0). One practice did not complete the MHI at time 3, and the time 2 values were carried forward to time point 3. Significant positive differences at the .05 level were found in the mean scores for the domains of organizational capacity, chronic condition management, and quality improvement and the overall total score. Significant improvement in scores between time 1 and time 2 occurred for these same categories and with the addition of the care coordination domain. Thus, significant changes in the overall MHI mean score as well as in specific domain mean scores were found among the 10 practices.

### Medical Home Index Mean Scores



**Figure 1.** Medical Home Index (MHI) results at year 1 (T1), year 2 (T2), and year 3 (T3). The MHI-full version has 25 indicators organized under 6 domains: (1) organizational capacity, (2) chronic condition management, (3) care coordination, (4) community outreach, (5) data management, and (6) quality improvement. Each indicator is scored on a scale of 1 to 8, with scores 1 to 2 defined as “level 1 to basic,” 3 to 4 as “level 2 to reactive,” 5 to 6 as “level 3 to proactive,” and 7 to 8 as “level 4 to comprehensive.” The total mean score shows a 33% increase overall in “medical homeness” for 10 medical home practices.

An observable set of qualitative changes occurred across all the 10 practices and included the following:

1. Practice engagement of patients and families in decisions about care redesign.
2. Identification of CYSHCN, assignment of a complexity level, and enrollment in a practice registry.
3. The expansion of roles for 1 or more staff to provide practice-based care coordination.
4. Development and monitoring of care plans (beginning with children who have the most complex conditions).
5. Delivery of care that is proactive and planned with the intention of increasing the value of the office visit (this includes performing previsit contacts with families to update all information prior to the appointment, having medical records readied for visits, and timing of visit duration being appropriately set).
6. Development of information for patients and families (eg, brochures, newsletters,

Web sites) was completed to communicate the best ways to access care, provide a medical home definition, and explain practice-based care coordination. These tools helped families to know what to expect from the practice and to better engage them in healthcare partnerships with their team.

During year 1, 30 or more families of CYSHCN per practice (>300 overall) were identified across all the 10 practices and asked to complete the MHFIS. Physician leaders identified children according to their understanding of who were affected by a special healthcare need; they then enrolled them in a practice CYSHCN registry. Of more than 300 survey mailings, 141 families responded to the presurvey (for a response rate of 47%). In year 3, or at least 24 months later, all 141 parents were mailed a postsurvey; 82 or 58% of the original sample responded. This created a matched pre- and post-data set made up of 82 families. Of these matched sets, 45 represented male children and youth and 37 female

**Table 1.** Medical Home Family Index and Survey pre- and postintervention results for 9 indicators as reported by a matched set of 82 families whose children with special health care needs are enrolled in the registry and receiving care from an improving primary care medical home

Survey item	Mean response	
	Preintervention at year 1	Postintervention at year 3
Seen by PCP in last year 1, <i>not at all</i> , through 4, <i>more than 10 times</i>	2.8	2.6 <sup>a</sup>
Seen by specialists in past year 1, <i>not at all</i> , through 4, <i>more than 10 times</i>	2.8	2.5 <sup>a</sup>
Separate hospitalizations in past year 1, <i>no stays</i> , through 4, <i>more than 10 stays</i>	1.4	1.2 <sup>b</sup>
Number of hospital nights last year 1, <i>no nights</i> , through 5, <i>&gt;2 weeks</i>	1.7	1.4 <sup>b</sup>
Absent school days 1, <i>no days</i> , through 4, <i>&gt;16 days</i>	1.7	1.5 <sup>b</sup>
Parental worry about child's health 1, <i>none</i> , through 5, <i>all the time</i>	3.5	3.1 <sup>a</sup>
Parental view of child's health 1, <i>excellent</i> , through 4, <i>poor</i>	2.1	1.8 <sup>a</sup>
Have a written care plan 0, <i>never</i> , through 3, <i>always</i>	0.59	1.01 <sup>b</sup>
Family feedback sought used ( <i>n</i> = 75) Percent <i>yes</i>	0.38	0.70 <sup>a</sup>

Abbreviation: PCP, primary care physician.

<sup>a</sup>*P* < .01.

<sup>b</sup>*P* < .05.

children and youth. The mean age was 9.2 years. The length of time their families had been with their primary care medical home averaged 7.4 years. The Child and Adolescent Health Measurement Initiative (CAHMI) screener for children with special healthcare needs was embedded into the MHFIS (Bethell et al., 2002). Ninety-eight percent of all surveys showed a positive CAHMI screener for these children, indicating a high level of concordance with physician identification.

According to family report, 9 indicators in the MHFIS showed significantly positive change between pre- and postmeasurements (*P* values < .05) (Table 1). These included a reduced number of primary care visits, reduced specialty visits, reduced hospitalizations, and decreased nights in the hospital. Functional indicators included fewer school days missed and reduced parental worry. One clinical in-

dicator showed lowered parental perception of the severity of their child's health status. Finally, satisfaction measures revealed an increase in the use of written care plans and evidence that families were being asked for their feedback about their experience of care and invited to suggest ideas for practice improvement/redesign.

The families who returned both pre- and postsurveys (*n* = 82) did not differ from those families who returned only the first survey (*n* = 141). There were no significant differences between the groups for child age (9.2 years vs 9.7 years) and child gender (53.7% men vs 50.8% men), Foundation for Accountability screener positive for chronic health condition (98% vs 93%), and mean length of time in the practice (7.4 years vs 6.3 years). The percentage of second time point responders ranged from 19% to 75% when examined

by practice site. The mean percentage for second time point responders by practice site was 42.8%. Overall, 58% of those completing the survey at the first time point completed a second survey.

Families responding to the survey were asked to identify the primary medical condition for their child from a list of 29 identified more common diagnoses compiled by CMHI. A final option was for families to indicate "other" if their child's condition was not on the list. When comparing the groups completing both surveys with those who completed only the first survey, the most common response in both groups was the "other" category. Of 141 children with special healthcare needs represented in the first sample, 40 are affected by 38 "other" conditions. The pediatricians in these medical homes are caring for children with more than 38 named more rare conditions including but not limited to Prader-Willi syndrome, bilateral Wilms tumor, Angelman syndrome, Hirschsprungs disease, mitochondrial disease, Rett syndrome, Turner syndrome, and esophageal atresia. Asthma was the next most commonly reported diagnosis for both groups. Attention deficit hyperactivity disorder (ADHD) and cerebral palsy were included in the top 6 most common diagnoses for both groups. Diabetes, however, was the 3rd most common diagnosis in the nonrespondent group to the second survey, while it was only the 10th most common diagnosis in the respondent group to the second survey. Asthma, autism, cerebral palsy, and ADHD were common to most of the practice sites in the respondent group.

### Family survey

The family survey asked specific questions about care coordination, quality of and satisfaction with the practice, utilization of services, and concern about their child with special healthcare needs. Composite scores were created for items that related to child concerns, care coordination, quality of practice, and satisfaction with practice. The mean composite scores were highly correlated and did not show significantly different changes

across the 2 surveys. Significant changes representing improvement across surveys were found for the items identified in Table 1. There were no significant negative changes in any of the survey items.

At the end of year 3, medical home improvement teams were asked: "What care processes are in place now that were not in place in year 1?" All teams (100%) reported that they had a practice-based care coordinator in place. One hundred percent stated that they were developing and using care plans, with 90% stating that they were able to carry out the actions outlined in the care plan. Eighty percent had developed a systematic method for identifying children with special healthcare needs in their practice, while 70% had also advanced to enrolling them into a paper or electronic registry. The teams planned to continue their improvement efforts, with parent partners remaining on all teams. Parental participation in the quality improvement team meetings did show some tapering by the end of the demonstration, with 40% of parents "present all the time," 20% "most of the time," and 40% "some of the time."

### DISCUSSION

While an implementation effort of small scope and budget, CMHI's project demonstrated that the efforts of 10 primary care practices to improve their "medical homes" resulted in significant clinical (1 indicator), functional (2 indicators), satisfaction (2 indicators), and utilization (4 indicators) outcomes for 82 families of CYSHCN who used the practices during the 3 years of the project. Families desiring team-based care, written care plans, and cross-organizational collaboration on behalf of their children will be better served in these improving medical homes. The efforts of these practice teams also demonstrate a 30% increase overall in their medical home indicators according to their self-assessment by using the MHI. Improvement was indeed seen after a year of intervention with the practices and was sustained through to the end of the

project. These data add a dimension to the accumulating evidence in support of a comprehensive community-based primary care medical home.

The original selection of children and families surveyed in each medical home included the practice's start-up CYSHCN registry; this created a potentially biased sample for the MHFIS. While every family asked to complete the survey had a child affected by a special healthcare need, it can only be assumed that those with the time, ability, and inclination to do so responded. Each primary care site began with families currently active with a practice and/or who was of most concern to their primary care provider at a given point in time. This may have created a sample of families with children who were currently in more urgent need of services and care or those who were more prone or able to access primary healthcare at that time. Families already managing multiple aspects of their children's health needs may not have been inclined to take the time to complete a survey. Multiple surveys returned included additional written comments either praising the efforts of their healthcare team or expressing frustration navigating a complex system with many gaps and little support. It is becoming more common for primary care networks to survey families, but they do not necessarily target a particular subpopulation for feedback. Multiple families reported "finally" being asked the right kinds of questions that they had not been asked be-

fore, such as about partnerships, care coordination, or difficulties with communications between primary and specialty care.

The MHFIS is not a validated measure but one developed by the CMHI to serve as a companion to the validated MHI. This article also does not provide a detailed discussion of the level of technical assistance and support needed to equip primary care practices to engage their families as partners in improvement, to use an improvement process, and to measure their own outcomes including improvements in the patient and family experience of care.

These data provide a positive example among multiple pilots and demonstration efforts to promote the implementation of the family-centered medical home in communities, to engage families/consumers in these efforts, and to demonstrate patient and provider outcomes. Such small projects are necessary but not sufficient to definitively demonstrate that the medical home achieves better results in healthcare utilization and in health, functional, and satisfaction outcomes at the levels of the patient, family, and staff of the family-centered medical home. Large, well-funded pediatric medical home demonstrations of considerable scope and duration are needed. Such demonstrations will need to examine further the value of integrated well, acute, and chronic pediatric care that is provided in partnership with families and comanaged with specialists and other team members.

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