Building Medical Homes: Improvement Strategies in Primary Care for Children With Special Health Care Needs

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ABSTRACT. Families and professionals agree that children and adolescents need access to community-based medical homes. This is especially true for children with special health care needs (CSHCN). Most primary care practices are designed for children's routine preventive and acute care needs. CSHCN benefit from care that is integrated with well-child and acute care; coordinated and actively co-managed with specialists, therapists, and educators; and offered in a planned, anticipatory manner. As the primary caregiver and decision maker, families need to be supported in a culturally effective way. Families want community resources that are integrated with care processes. Primary care practices that serve CSHCN require a practical and effective improvement method to become fully realized medical homes. A change method, which blends improvement strategies with progressive measurement, must be perceived by practices as practical and helpful, and it must be supported. The Center for Medical Home Improvement has developed and tested an effective model of medical home improvement and tools to measure the status of a practice and its progress of change. *Pediatrics* 2004;113:1499–1506; *children with special health care needs, medical home, quality improvement, primary care, care coordination, family-centered care.*

ABBREVIATIONS. CSHCN, children with special health care needs; MCHB, Maternal and Child Health Bureau; AAP, American Academy of Pediatrics; CMHI, Center for Medical Home Improvement; MHI, Medical Home Index; MHFI, Medical Home Family Index; CVC, clinical value compass.

Most families and professionals agree that children need access to a medical home.[1,2] The medical home is a health care model for all children, but for children with special health care needs (CSHCN), it assumes greater importance as a centralizing "headquarters" for necessary information, care coordination, and advocacy.[3]

As defined by the US Maternal and Child Health Bureau (MCHB) and the American Academy of Pediatrics (AAP), the medical home provides care that is accessible, family centered, continuous, comprehensive, coordinated, compassionate, and culturally effective.[4,5] The AAP endorsement of the medical home concept is reiterated in its latest policy state-

ment[5] and highlighted as a strategic priority for the organization. The medical home is a critical element of US public health policy for CSHCN as a major element of the 2010 action agenda of the MCHB.[4] These policies address the gap between what the reality of health care is for CSHCN and what is needed to better meet the special needs of these children. For a primary care practice that serves children to become a medical home, a practical and effective practice improvement method is needed. This method must include the use of a validated measurement of "medical homeness" to establish a baseline describing current practice and planned changes and to measure resulting improvements.

The Center for Medical Home Improvement (CMHI) within the Hood Center for Children and Families at the Children's Hospital at Dartmouth Hitchcock Medical Center has developed a family-centered medical home improvement model and a validated measure, the Medical Home Index (MHI), to assess medical homeness. The model and measures are described in the tool kit "Building a Medical Home: Improvement Strategies in Primary Care for Children With Special Health Care Needs."[6] The tool kit includes improvement steps and strategies as well as measurement tools implemented by practices in New England and other regions. The CMHI mission is to establish and support networks of parent/professional teams to improve the quality of care for children and youths with special health care needs and their families. In keeping with this mission, its model blends parent participation, professional knowledge, and care coordination to improve care using a consumer-informed quality improvement process. This article describes the CMHI method and tools and the outcomes of their implementation.

THE MEDICAL HOME FOR CSHCN

As defined by the MCHB, CSHCN have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions that require health and related services of a type or an amount beyond that required by children generally.[7] In the United States, 12.5 million children fit this definition. Although composing 15% to 18% of children in the US, CSHCN account for 80% of pediatric health care expenses.[8] This group of children has grown by 30% over the past 2 decades, largely as a result of improved diagnosis and early identification; enhanced survival from premature birth, birth defects, and chronic illnesses; and better access to specialized care. CSHCN have > 2.5 times the number of school

absences, twice as many unmet health needs, and almost 2.5 times as many contacts with physicians, and they account for > 5 times as many hospital days per 1000 as children generally.[8]

The comprehensive health needs of these children and adolescents do not fit with the services traditionally offered by the primary care system, which is designed for the 80% of children who do not have special needs. Primary care practices are organized to provide routine well-child care and acute illness management based on the individual patient–provider encounter. Well-child and preventive care for CSHCN must include a model of chronic condition management.[1,9] Chronic condition management requires the capacity to identify and monitor CSHCN, coordinate and systematically plan for their care, collaborate with specialists and community agencies, and advocate for their needs, all in partnership with their families.[1]

A community-based medical home coordinates a set of relationships among health and educational professionals in varied settings, defines and interprets the roles of multiple clinicians, and advocates for needed services and payer support. Relationships at the community level exist among schools, early intervention programs, family support services, and parent-to-parent organizations.[10] As a centralizing "home base" or "headquarters" for care, the medical home focuses on the dynamic needs of children and families and offers systematic yet individualized responses. Families receive support and advocacy from a trusted health professional at different points in time as needed. Practice-based care coordination is provided in partnership with the family and helps with connections to other resources and services.[11,12] The care coordinator's services are grounded in the elements of family-centered care and bolster the family's central role in their child's health care (Fig 1).[13]

METHODS

Obstacles to improving primary care for CSHCN include 1) a lack of office-based data or registry systems that support systematic approaches to the population of CSHCN; 2) roles that are not explicitly defined among parents, primary care health professionals, and others; 3) reimbursement systems that respond to well-child and acute illness care but that are inadequate for many services, such as comprehensive, coordinated care; 4) a lack of effective strategies for implementing practice changes or improvements; and 5) limited or nonexistent consumer (parent) involvement in the design and evaluation of care.

Introducing change into a busy primary care pediatric practice is like trying to repair a bicycle while riding it. Even the most motivated practice finds change difficult to implement. Many primary care providers believe that implementing the medical home concept is the right thing to do but question how they can do so and remain solvent. Change must emanate from within practice organizations and requires a commitment of time, energy, and adherence to a systematic but incremental process. Ultimately, improvement activity that is clear, supportive, and practical must become integral to the ongoing work of the organization.

A Vision and a Map for Change

Practices that use the CMHI process to make medical home improvements are guided through the following steps: 1) baseline measurement, 2) team formation, 3) learning medical home quality improvement structure and process implementation, and 4) collaborative learning. Baseline measurements assess initial indicators of the practice's medical homeness and of clinical, functional, satisfaction, and cost measures for CSHCN in the practice. Team formation involves creating a medical home improvement team for the practice, including a lead physician, an office staff member who will develop the role of the care coordinator within the practice, and 2 "parent partners" who have CSHCN. Team members make a commitment to the medical home concept and to the time necessary to improve the process of care. They participate in quality improvement training and hold regular team meetings to plan, design, implement, and measure improvements. The CMHI provides facilitation support to these meetings, connects practice improvement teams with existing tools and materials to assist in their efforts, and provides a communication link among the participating practices.

The CMHI convenes collaborative learning sessions, bringing multiple medical home improvement teams together for retreats,
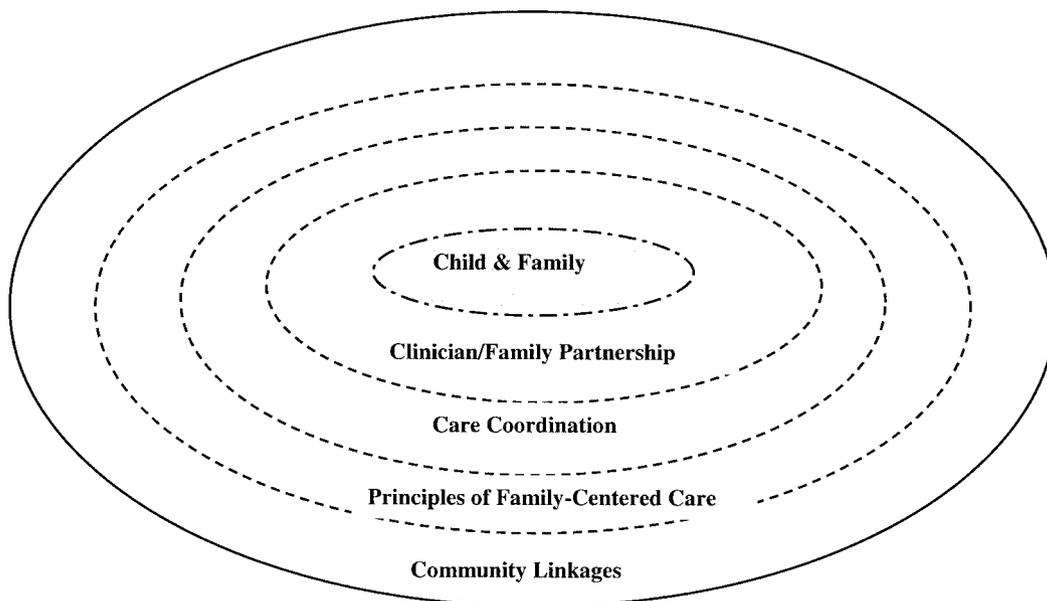

Fig 1. The medical home: child and family in partnership with professional clinicians. They share care coordination responsibilities that are embedded in the principles of family-centered care; links to professionals and agencies within the community are supported and strengthened.

telephone conferences, and web-based interactions. Teams learn to have efficient and productive meetings and to implement and evaluate their changes using an approach called "rapid cycle improvement."[14,15] Over time, teams become increasingly independent and are able to translate their improvement skills to other practice needs or emerging family concerns.

Medical Home Measurement and Improvement

Medical home status can be measured at many different levels. Population measures have been developed under the Health Resources and Services Administration/MCHB.[16] This project extracted medical home data from existing surveys such as the National Survey of Children With Special Health Care Needs and the Medical Expenditure Panel Survey and incorporated measures into the new National Children's Health Survey.[16] Although they can determine the number of children who receive care in a medical home, population measurements do not indicate the quality of care within a given practice.

Until recently, the absence of a valid practice-level measurement tool has hampered improvement efforts and prevented the collection of data to establish the relationship between the medical home model and enhanced outcomes for CSHCN and their families. In 2001, the CMHI developed and validated a measure of medical homeness, the Medical Home Index (MHI), which is designed to quantify the concept at the practice level.[17,18] A companion tool, the Medical Home Family Index (MHFI), measures the family experience of care received within a particular practice. The CMHI uses the MHFI combined with additional survey instruments as a broad assessment of child and family outcomes.

The MHI provides a point-in-time assessment of the implementation of medical home elements. The MHI contains a total of 25 items or themes that are divided into 6 domains of practice activity that are critical to the quality of care in a medical home: 1) organizational capacity, 2) chronic condition management, 3) care coordination, 4) community outreach, 5) data management, and 6) quality improvement (Table 1). A practice scores itself for each theme across 4 levels of achievement corresponding to a continuum of quality starting with good basic pediatric care (level 1) through responsive care (level 2), proactive care (level 3), and comprehensive care (level 4). Figure 2 is an example of a domain (organizational capacity) and its themes (family feedback) to illustrate the 4 levels of quality. Each theme can receive a score from 1 (partial achievement of level 1) to 8 (complete achievement of level 4) so that, with 25 themes, a practice can be scored across a range from 25 to 200 points. (The raw summary scores with a range of 25-200 were ultimately transformed to a scale of 1–100 to facilitate interpretation of scores.) Construct validation was established for the MHI to determine its faithfulness and clarity in representing the medical home concepts and values. Twenty-three national medical home experts completed a review of the original tool, which led to a final abbreviated version. Staff from a regional and national sample of pediatric primary care practices then completed the MHI and spent 90 minutes in an on-site interview with CMHI staff. Practice index scores on the MHI were collected, interrater reliability between project staff and between the practices and project staff was examined, and the internal consistency of the MHI domains and themes was studied. Kappa coefficients of interrater reliability were calculated, and internal consistency reliability α coefficients were determined.[17,18] The entire MHI and MHFI can be viewed and downloaded as a PDF file at www.medicalhomeimprovement.org, and guidelines for its use can be obtained from the CMHI.
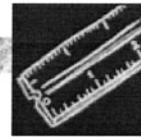
"Not everything that can be counted counts, and not everything that counts can be counted" (Albert Einstein, attributed). This is particularly relevant when attempting to isolate and quantify patient care. For example, according to the AAP definition, medical homes provide compassionate care. Compassion is a difficult concept to measure. MHFI asks families to describe the behaviors and practices that make up the compassion that they need from their medical home. In samples from > 300 families, compassionate care is manifested by providers who listen unhurriedly, communicate clearly, and validate family experiences and perspectives (CMHI unpublished data, 2003).

Systematic structures and processes that support these indicators of compassion can be built into the medical home's delivery of care. Practices can implement structures that promote an environment that is conducive to listening while preventing the need to rush. For example, the electronic identification of CSHCN can alert reception staff that additional time may be needed for a less hurried visit, allowing time to listen and identify family concerns. It can also prevent children and families from being asked to return another day for a longer visit as a result of inadequate time budgeted for the current appointment. Such simple changes may ease family stress and enhance their ability to care effectively for their children. They can be measured with the MHI and the MHFI.

Improvement teams use data from their own measures of change in real time to determine whether their changes have improved care. These measurements then illustrate outcomes as an effective result of rapid cycle improvement. They include practice improvements in CSHCN identification, CSHCN stratification by complexity, care-coordination activities, and ways to measure family satisfaction with care.

TABLE 1. Medical Home Index: 6 Domains and 25 Themes

Domains	Themes
1. Organizational capacity	1.1 Mission of the practice
	1.2 Communication/access
	1.3 Access to medical records
	1.4 Office environment
	1.5 Family feedback
	1.6 Cultural competence
	1.7 Staff education
2. Chronic condition management	2.1 Identification of CSHCN
	2.2 Care continuity
	2.3 Continuity across settings
	2.4 Cooperative management with specialists
	2.5 Supporting transition to adult services
	2.6 Family support
3. Care coordination	3.1 Role definition
	3.2 Family involvement
	3.3 Child and family education
	3.4 Assessment of needs/plans of care
	3.5 Resource information and referrals
	3.6 Advocacy
4. Community outreach	4.1 Community assessment of needs of CSHCN
	4.2 Community outreach to agencies and schools
5. Data management	5.1 Electronic data support
	5.2 Data retrieval capacity
6. Quality improvement	6.1 Quality standards (structures)
	6.2 Quality activities (processes)

Domain 1: Organizational Capacity: For CSHCN and Their Families

THEME:	Level 1	Level 2	Level 3	Level 4
#1.1 The Mission of the Practice	Primary care providers (PCPs) at the practice have individual ways of delivering care to children with special health care needs CSHCN; their own education, experience and interests drive care quality. ☐ PARTIAL ☐ COMPLETE	Approaches to the care of CSHCN at the practice are child rather than family-centered; office needs drive the implementation of care (e.g. the process of carrying out care). ☐ PARTIAL ☐ COMPLETE	The practice uses a family-centered approach to care (see page 2), they assess CSHCN and the needs of their families in accordance with its mission; feedback is solicited from families and influences office policies (e.g. the way things are done). ☐ PARTIAL ☐ COMPLETE	In addition to Level 3, a parent/ practice "advisory group" promotes family-centered strategies, practices and policies (e.g. enhanced communication methods or systematic inquiry of family concerns/priorities); a written, visible mission statement reflects practice commitment to quality care for CSHCN and their families. ☐ PARTIAL ☐ COMPLETE
#1.2 Communi- cation/ Access	Communication between the family and the PCP occurs as a result of family inquiry; PCP contacts with the family are for test result delivery or planned medical follow-up. ☐ PARTIAL ☐ COMPLETE	In addition to Level 1, standardized office communication methods are identified to the family by the practice (e.g. call-in hours, phone triage for questions, or provider call back hours). ☐ PARTIAL ☐ COMPLETE	Practice and family communicate at agreed upon intervals and both agree on "best time and way to contact me"; individual needs prompt weekend or other special appointments. ☐ PARTIAL ☐ COMPLETE	In addition to Level 3, office activities encourage individual requests for flexible access; access and communication preferences are documented in the care plan and used by other practice staff (e.g. fax, e-mail or web messages, home, school or residential care visits). ☐ PARTIAL ☐ COMPLETE
#1.3 Access to the Medical Record *Requires both MD & key non-MD staff person's perspective.*	A policy of access to medical records is not routinely discussed with families; records are provided only upon request. ☐ PARTIAL ☐ COMPLETE	In addition to Level 1, it is established among staff that families can review their child's record (but this fact is not explicitly shared with families). ☐ PARTIAL ☐ COMPLETE	All families are informed that they have access to their child's record; staff facilitates access within 24-48 hours. ☐ PARTIAL ☐ COMPLETE	In addition to Level 3, practice orientation materials include information on record access; staff locate space for families to read their child's record and make themselves available to answer questions. ☐ PARTIAL ☐ COMPLETE
#1.4 Office Environment *Requires both MD & key non-MD staff person's perspective.*	Special needs concerning physical access and other visit accommodations are considered at the time of the appointment and are met if possible. ☐ PARTIAL ☐ COMPLETE	Assessments are made during the visit of children with special health care needs and the needs of their families; any physical access & other visit accommodation needs are addressed at the visit and are documented for future encounters. ☐ PARTIAL ☐ COMPLETE	In addition to Level 2, staff ask about any new or pre-existing physical and social needs when scheduling appointments; chart documentation is updated and staff are informed/prepared ahead of time ensuring continuity of care. ☐ PARTIAL ☐ COMPLETE	In addition to Level 3, key staff identify children scheduled each day with special health care needs, prepare for their visit and assess and document new needs at the visit; an office care coordinator prepares both office staff and the office environment for the visit; s/he advocates for changes (office/environmental) as needed. ☐ PARTIAL ☐ COMPLETE
#1.5 Family Feedback *Requires both MD & key non-MD staff person's perspective.*	Family feedback to the practice occurs through external mechanisms such as satisfaction surveys issued by a health plan; this information is not always shared with practice staff. ☐ PARTIAL ☐ COMPLETE	Feedback from families of CSHCN is elicited sporadically by individual practice providers or by a suggestion box; this feedback is shared informally with other providers and staff. ☐ PARTIAL ☐ COMPLETE	Feedback from families of CSHCN regarding their perception of care is gathered through systematic methods (e.g. surveys, focus groups, or interviews); there is a process for staff to review this feedback and to begin problem solving. ☐ PARTIAL ☐ COMPLETE	In addition to Level 3, an advisory process is in place with families of CSHCN which helps to identify needs and implement creative solutions; there are tangible supports to enable families to participate in these activities (e.g. childcare or parent stipends). ☐ PARTIAL ☐ COMPLETE
#1.6 Cultural Competence	The primary care provider (PCP) attempts to overcome obstacles of language, literacy, or personal preferences on a case by case basis when confronted with barriers to care. ☐ PARTIAL ☐ COMPLETE	In addition to Level 1, resources and information are available for families of the most common diverse cultural backgrounds; others are assisted individually through efforts to obtain translators or to access information from outside sources. ☐ PARTIAL ☐ COMPLETE	In addition to Level 2, materials are available and appropriate for non-English speaking families, those with limited literacy; these materials are appropriate to the developmental level of the child/young adult. ☐ PARTIAL ☐ COMPLETE	In addition to Level 3, family assessments include pertinent cultural information, particularly about health beliefs; this information is incorporated into care plans; the practice uses these encounters to assess patient & community cultural needs. ☐ PARTIAL ☐ COMPLETE

Instructions: A) Please select and circle one level from Levels 1, 2 3, or 4 for each theme above (circle one).
B) Then indicate whether you place your practice at a PARTIAL or COMPLETE ranking within that level (circle one).

Fig 2. Sample domain "organizational capacity" from the MHI.

Medical Home Improvement Implementation

Quality improvement is domain 6 of the MHI; its highest level of achievement in a practice requires a practice improvement team inclusive of families of CSHCN as partners. The purpose of this team is to implement and measure medical home improvements within the structures and processes of care at the practice. A medical home that is successful at quality improvement requires a practice change process method and a commitment to activities that will bring about prioritized improvements.

The CMHI works with multiple practice teams by supporting and facilitating a process of incremental medical home improvements. The practice teams are the architects of change in their

practice. Their first step is to complete a practice assessment using the MHI. Improvement team "parent partners" (as well as a larger sample of families from the practice) complete the MHFI. Both indices help the teams see the strengths and weaknesses of the practice and identify areas for improvement. Brainstorming stimulates team members to list all improvement ideas that emerge from their practice assessments. Teams develop a list of blended ideas, which is used to guide future improvements. A multivoting process is used to assist teams to prioritize their ideas and select an initial improvement project. The selected improvement will be the one that is most highly valued by the team as a whole.

The teams use their prioritized improvement idea to create their first "aim statement." The aim statement clarifies what the team wants to improve, for whom, and by when. For example, broad aim statements might be "to improve communication among the child, family, and team of child health professionals during the office visit," "to improve the coordination of care for CSHCN," "to improve access to community resources," or "to improve access to condition-specific information for parents of children with chronic conditions." The teams then work to refine their aim and express it in operational terms.

To avoid nonsustainable "quick fixes," teams identify outcomes that they believe will result from successful implementation of their aim. Facilitation helps them examine their aim, determine what they are trying to improve and for whom, and decide how they will know that their change is an improvement. These steps create the groundwork for the outcome measurements that teams will use and forces clarification and specification.

The CMHI uses the clinical value compass (CVC) as a structure for measured, incremental improvement.[14,15] The CVC was designed for continuous quality improvement processes in small organizational groups that provide health care services. Rather than focus only on cost reduction, the CVC defines 4 outcome dimensions: 1) clinical/biological, 2) functional, 3) satisfaction, and 4) cost. Teams attempt to select at least 1 measure from each of the 4 "compass points" for each improvement project. Outcomes are considered from the child, family, and practice perspectives. For example, reduced stress/worry or improved caregiving competence might be functional outcomes from the family or parental perspective.

Once outcomes for the improvement project's aim are selected, simple operational measures are identified to obtain data to document that an improvement is having the desired effect. If the team is working to improve communication, then reduced stress may be one of the matched outcomes to measure. A question about parental worry in the past 3 months would be a measurement matched to this indicator. Figure 3 outlines a CVC developed by the CMHI to depict possible medical home outcome measures for all 4 points on the compass. The CVC is used to assist teams in their own selection of outcomes and measurements and as a program evaluation guide for CMHI initiatives.

Once the team's aim, outcomes, and measures are defined, the team develops a plan for improvement that will be implemented, studied, and refined. This follows the rapid cycle quality improvement method using plan, do, study, and act cycles.[14] Improvement cycles follow one another logically and incrementally in steps of increasing complexity. The CMHI worksheets are used to provide a map or template for the work of improvement teams. Worksheets include the aim, outcomes plotted around the CVC, and the plan for improvement. Teams use this "map" to reorient themselves to their original ideas to stay their course. Teams are encouraged to reflect on and celebrate their successes and share them with other teams, colleagues, and friends.

With time, improvement activities become an integral part of the office ecology. Teams learn to create their own measures and use the resulting data to demonstrate the value of the medical home to parents, colleagues, managed care organizations, and policy makers. Typically, teams measure their success with population identification, assignment of complexity scores, provision of care coordination and care plans, and documentation of care coordination activities. Improvements thus are developed, implemented, evaluated, and owned by the practice team.

The "microsystem" (Fig 4) illustrates the overall process of providing a medical home as a series of small, replicable service units, or microunits.[15,19] The CMHI uses the microsystem to illustrate opportunities for implementing improvement strategies in the flow of patient care. Microunits include patient orientation to the practice; management of office visits; chronic condition management blended with acute and preventive care; and community outreach activities including care follow-up, advocacy, and communication with other organizations (eg, specialists, schools, agencies). The microunit perspective allows an overlay of learning about child and family needs, which "feeds forward" in real time into individual office visits and "feeds back" to inform ongoing improvement. Figure 4 shows the elements of the microsystem (orientation, visits, chronic condition management, and community outreach) and improvement strategy examples for each microunit implemented by practice improvement teams that work with the CMHI.

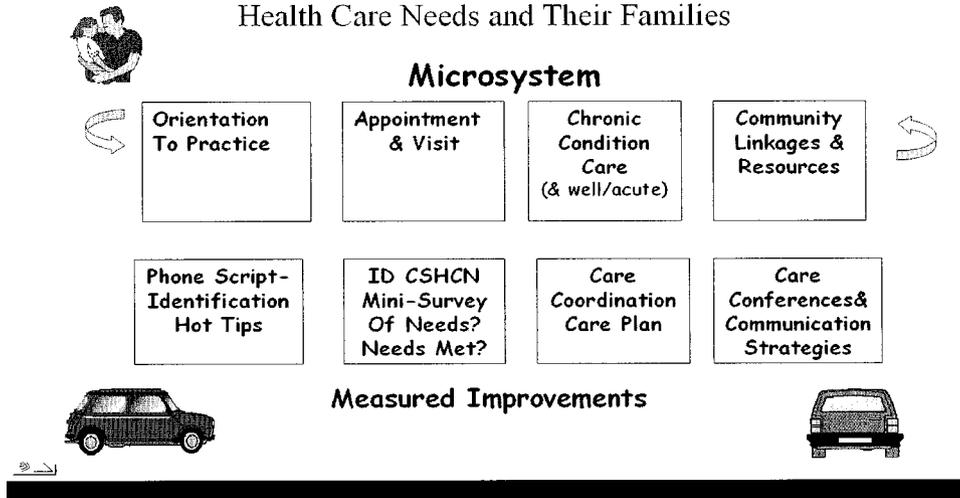**Fig 3.** CVC for the medical home. dx, diagnosis; rx, treatment.
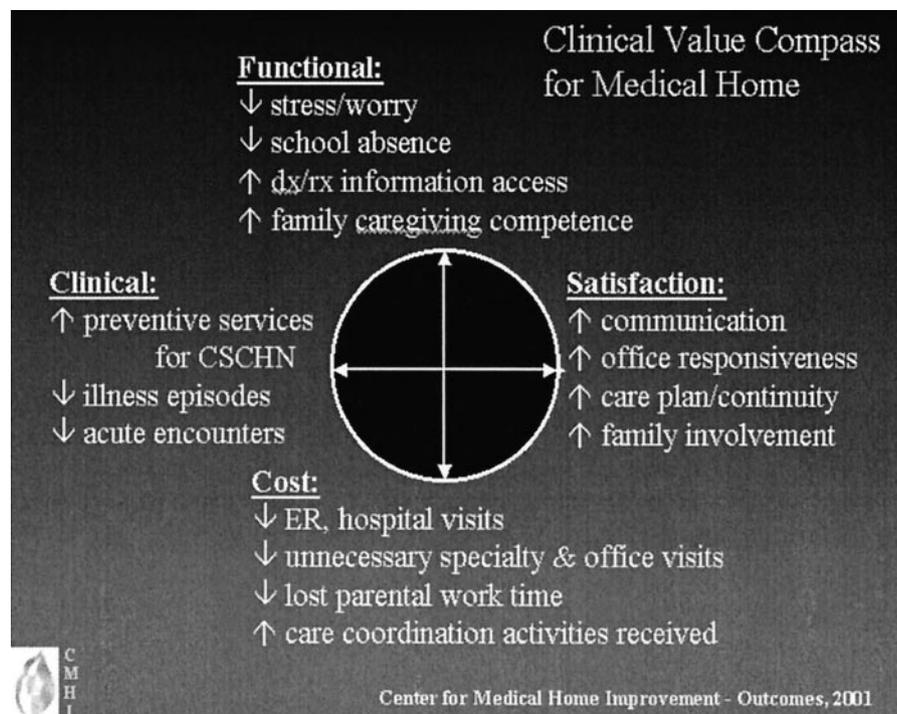
Fig 4. "Microsystem" for the medical home with improvement examples.

EXAMPLES OF MEDICAL HOME IMPROVEMENT

In the CMHI model, newer practice improvement teams have benefited from the earlier work and mentoring of more experienced teams by using or modifying their tools and interventions. Most teams recognize the need to establish a practice definition of CSHCN. These interpretations typically draw on the definition established by the MCHB.[7] They may include a combination of functional and service utilization descriptions (condition lasting longer than 1 year, affecting daily life, requiring special services or supports) and a categorical listing of common conditions. One practice team chose to distinguish biological, psychological, emotional/behavioral, and at-risk categories with examples of diagnoses in each category to prompt their identification process. No practice has been inclined to use rigid screening tools for inclusion of children in their identified population but rather a guided prospective process of informed practitioner identification and family confirmation. Each practice team developed a method for ongoing monitoring of the identified CSHCN within the practice. Registries of their population and computerized fields within their patient registration databases are used. External chart identifiers also support the ongoing responsiveness of the practice to the needs of CSHCN (eg, reminders to have a quiet room ready, referencing and updating established care plans).

Once the CSHCN definition and processes for identification and monitoring are established, practice teams embark on a more diverse set of improvement aims, outcomes, and related project plans. The development of the role of a practice-based care coordinator is often a focus for improvement (Table 2). Care plans frequently become a tool that care coordinators use in their work with children and families. As each practice develops the care coordination role, comprehends the value of this activity, and determines that care coordination is an essential medical home service, improvement teams begin to consider the sustainability of the position.

The medical home improvement team at Exeter Pediatrics Associates (Exeter, NH) decided to keep track of the number of CSHCN identified as its first step. They subsequently developed short pre and post visit surveys for parents to complete. The previsit survey identified the main parental concern or issue for the visit, and the postvisit survey inquired whether the concern had been addressed. The survey prompts parents to express concerns beyond typical medical issues and gives health professionals a tool for a more effective dialogue with parents. The Exeter Pediatrics Associates care coordinator also used the survey to refine her role to serve CSHCN more effectively. As a result, the previsit survey also asked whether parents knew about and had used the care coordinator. During the first year, Exeter Pediatrics Associates identified 1600 CSHCN, tracked the main concern of families for their children at the time of the visit (eg, keeping up with school, developmental issues, concerns for the future), and

TABLE 2. Practice-Based Care Coordination in the Medical Home

Definition Source	Definition
AAP Committee on Children With Disabilities	Care coordination is a process that links CSHCN and their families to services and resources in a coordinated effort to maximize the potential of children and provide them with optimal health care.[1]
Practice-Based Care Coordination in the Medical Home (CMHI)	Medical home care coordination is a practice-based, proactive, family-centered process of teamwork designed to 1. Establish practice medical homeness for CSHCN and their families 2. Enable timely access to the PCP and practice services and resources 3. Build bridges among families and health, education, and social services promoting continuity of care 4. Facilitate family access to referrals, information, and education across multiple systems 5. Maximize effective, efficient, and innovative use of existing resources

PCP indicates primary care provider.

learned that most families did not know about their care coordinator. This information led easily to the next project, which was the development of a simple brochure describing the care coordinator role and how to make contact. The brochure also educates families, community agencies, and even tertiary medical centers about Exeter Pediatrics Associates and the availability of their practice-based care coordinator.

The medical home improvement team at Upper Valley Pediatrics (Bradford, VT) identified the need to schedule "chronic condition management" office visits to review child and family needs on a regular basis proactively rather than respond to acute needs reactively. They developed a tool to guide and record these visits, which includes the identification of concerns, action plans, party responsible for action, and follow-up plans. Their practice-based care coordinator uses these tools to guide coordination visits.

Dartmouth Hitchcock–Plymouth Pediatrics and Adolescent Medicine (Plymouth, NH) chose to begin with a community-oriented project. They joined with their local hospital to begin an educational series for the community on CSHCN. They focused first on the needs of children with attention-deficit/hyperactivity disorder. This led to established partnerships with parents and the local school system to create and use common care plans for all adults involved with the child's family life, education, and health care to offer a continuous approach in all settings. The practice has since developed a specific process for intake, evaluation, and monitoring of children with attention-deficit/hyperactivity disorder that improves the consistency of approach and communication feedback loops with key community agencies such as schools.

Gifford Pediatrics (Randolph, VT) set out to improve communication with schools about all children with chronic health conditions. A series of community forums resulted in the creation of a unique information exchange tool for use among families, schools, and the practice. This information exchange places families at the center of the flow of their child's health care and school information. These forums were unusually intense at first and highlighted an apparent discomfort that school officials had with this central role for parents as advocated by the pediatric practice staff. Evaluation was accomplished through surveys of families and school staff regarding the value of the information exchange form and the training about its use. Follow-up meetings have led to improved relationships, dialogue, and mutual respect among all participants. The lessons learned and tools developed by these veteran teams are fed forward into subsequent medical home improvement team efforts.

LESSONS LEARNED

Each practice improvement team has followed its own individual path, but 3 common elements have emerged as critical to improving medical homeness: systematic identification of the practice's population of CSHCN, involvement of parent partners (consumers) in the improvement process, and development of the role of a practice-based care coordinator. The care coordinator tends to divide efforts among systems and implementation activities, care coordination service delivery to patients, and community outreach and communication. Each team depends on physician/leader commitment to the improvement process and to the work of the team. Families of CSHCN bring the consumer perspective, innovative ideas, and critical assessment of office efficiency.

Successful family experiences with primary care practices are not solely dependent on the quality of their interactions with physicians and other child health professionals. Front-line reception and telephone staff, office nurses, medical assistants, referral specialists, and the medical records and billing staff contribute to the overall quality of a medical home. Improvement teams need to plan for effective interactions and communication with these and other staff.

Ultimately, as the work of improvement teams proceeds, the medical home "office system" becomes a reality. Access will be improved. Children and families are more likely to be known to their health care professionals and staff. Availability of resources within the family is more likely to be known. Potentially, more treatment options are available. Together, families and staff at a medical home choose the most current and reliable care for the child's condition. The practice establishes effective relationships with families to integrate and co-manage care with specialists, therapists, and other agencies. Medical home providers, staff, and families engage in a collaborative relationship of caring and learning.

CONCLUSIONS

The first step in the process of legitimizing the value of the medical home concept for the provision of children's health care involved strategies to operationalize the concept's basic elements. This was necessary to identify, define, and articulate specific observable services, behaviors, and characteristics of the medical home model in practice. The CMHI medical home model of improvement has provided dozens of practices in multiple states with a manageable and effective process for implementing methods of improved care for CSHCN.

Second, the experience of practices has helped with the development of a reliable measurement tool to assess the degree to which a practice manifests medical home characteristics. The CMHI has developed and validated the MHI and its companion instrument, the MHFI, to allow for a combination of numerical practice self-assessment and consumer perspective as dual measures of medical home implementation.

Third, the experience of individual primary care practices partnering with families to redesign care that targets the medical home model must be linked with state and national medical home efforts. In accordance with MCHB guidance, states are reporting on their progress toward the Healthy People 2010 action agenda outcome measure that all CSHCN have access to care provided from a medical home. The use of the MHI as a validated measure of medical homeness allows state programs to recognize medical home efforts and support their improvement. States have an opportunity to identify high-quality medical homes and support access for all CSHCN. The CMHI MHI is useful to public and private payers for setting enhanced medical home reimbursement thresholds. In addition, state Title V and Medicaid/State Child Health Insurance Program leaders and providers of pediatric care can forge partnerships for spreading medical home improvement strategies through regional networks.

For all constituencies, there is a need to demonstrate that outcomes for children and families are improved when care is provided in a medical home. The continued development of medical home quality improvement activities is dependent on an effective "spread" strategy. Learning from families and using their input to redesign care should guide all medical home improvement efforts. The AAP has made the medical home for all children one of its highest priorities. The AAP National Center for Medical Home Initiatives for Children With Special Needs is a natural partner for improvement and spread efforts. The establishment of medical homes becomes a vital community resource for all children and CSHCN and their families. The goal of comprehensive care within a medical home can be realized through this quality improvement process. The movement toward this approach to improved health care for CSHCN not only reduces the stress on the pediatric health care dollar and improves health outcomes but

also improves the quality of life for CSHCN and their families.

REFERENCES

1. American Academy of Pediatrics, Committee on Children with Disabilities. Care coordination: integrating health and related systems of care for children with special health care needs. *Pediatrics.* 1999;104:978–981
2. Starfield B. *Primary Care: Balancing Health Needs, Services, and Technology.* New York, NY: Oxford University Press; 1998
3. Johnson CP, Blasco PA. Community resources for children with special health care needs. *Pediatr Ann.* 1997;26:679–686
4. US Department of Health and Human Services, Health Resources and Services Administration. *Measuring Success for Healthy People 2010: National Agenda for Children With Special Health Care Needs.* Rockville, MD: US Department of Health and Human Services; 1999
5. American Academy of Pediatrics. Policy statement: the medical home. *Pediatrics.* 2002;110:184–186
6. Center for Medical Home Improvement. *Medical Home: Improvement Kit.* Lebanon, NH: Hood Center for Children and Families, Children's Hospital at Dartmouth Hitchcock Medical Center; 2001
7. McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics.* 1998;102(suppl):137–142
8. Newacheck PW, Strickland B, Shonkoff JP, et al. An epidemiologic profile of children with special health care needs. *Pediatrics.* 1998; 102(suppl):117–123
9. American Academy of Pediatrics, Committee on Community Health Services. The pediatrician's role in community pediatrics. *Pediatrics.* 1999;103:1304–1307
10. FamilyVoices. *The Health Care Experiences of Families of Children With Special Health Care Needs: Summary of National and California Survey Results.* Albuquerque, NM: Family Voices, Inc; 1998. Available at: www.familyvoices.org/publist.html. Accessed May 12, 2003
11. Jeppson ES, Thomas J. *Essential Allies: Families as Advisors.* Bethesda, MD: Institute for Family Centered Care; 1997
12. Cooley WC, McAllister JW. Putting family centered care into practice—a response to the adaptive practice model. *J Dev Behav Pediatr.* 1999;20:120–122
13. Cooley WC, Olson A. Developing family-centered care for families of children with special health care needs. In: Singer GHS, Powers LE, Olson AL, eds. *Redefining Family Support—Innovations in Public-Private Partnerships.* Baltimore, MD: Paul Brookes; 1996:239–257
14. Nelson EC, Mohr JJ, Batalden PB, Plume SK. Improving health care part 1: the clinical values compass. *Jt Comm J Qual Improv.* 1996;22:243–256
15. Nelson EC, Splaine M, Godfrey MM, et al. Using data to improve medical practice by measuring processes and outcomes of care. *Jt Comm J Qual Improv.* 2000;26:667–685
16. Bethell C. Population Based Measurement of the Medical Home. Presented at the Fourth Annual Child Health Services Research Meeting; June 28, 2002; Washington, DC
17. Cooley WC, McAllister JW, Sherrieb KA, Clark RE. Medical Home Index: Validation of a Primary Care Quality Measurement Tool. 130th Annual Meeting of American Public Health Association. November 11, 2002. Philadelphia, PA (abstr 48361)
18. Cooley WC, McAllister JW, Sherrieb K, Clark RE. The Medical Home Index: development and validation of a new practice-level measure of implementation of the medical home model. *Ambul Pediatr.* 2003;3: 173–180
19. Nelson EC, Batalden PB, Mohr JJ, Plume SK. Building a quality future. *Front Health Serv Manage.* 1998;15:3–32

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