Medical Home 2009: What It Is, Where We Were, and Where We Are Today

Ten years ago, most Americans would have said their only real concern with our healthcare system was its rising costs and the significant number of Americans without insurance. Now most Americans, and certainly American policymakers, view the high cost of U.S. healthcare as only one symptom of a system that is itself gravely ill. Another symptom is our system's poor results reflected by its poor ranking across an array of health indicators and measures of quality of care.

**HEALTH SYSTEMS THAT WORK**

As policymakers look for solutions to this broad system dysfunction — high cost and poor outcomes — they have rediscovered a model of care that, while never absent from the American scene, has long been in eclipse. Primary care, "... the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal healthcare needs, developing a sustained partnership with patients, and practicing in the context of family and community," is now touted as critical to successful healthcare system reform. This emphasis on effective primary care as the basis for a functional health system rests on solid health services research examining systems both in the United States and abroad, consistently showing a strong association between systems with strong primary care and both better outcomes and lower cost. Ironically, this rediscovery of primary care comes at a time when careers in primary care, particularly for adults, have become unattractive to debt-burdened medical students.

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who regard primary care as undervalued with relatively lower incomes, longer work hours, less prestige, and an increasingly constrained scope of practice.

CHANGING EPIDEMIOLOGY: IS PRIMARY CARE UP TO THE CHALLENGE?

Although one stream of evidence highlights the potential role for primary care, other evidence suggests that primary care as traditionally organized and practiced in the United States may not address the evolving health needs of our society, including its children. Modern medicine initially focused on common acute medical issues such as acute infectious diseases. Yet the major drivers of both cost and disability in the United States, both for adults and children, are now chronic conditions. The proportion of children and youth with chronic conditions has increased dramatically because of higher rates of conditions such as obesity, asthma, attention deficit hyperactivity disorder, and depression, and enhanced survival of children/youth with formerly fatal conditions such as sickle cell disease and cystic fibrosis.

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PATIENT PERSPECTIVES

Survey data collected from families are remarkably consistent in identifying what parents of children and youth with special healthcare needs (CYSHCN) want for their children.
want care that is timely and technically expert, resulting in the right diagnosis, the right treatment, the right procedures, and the right follow-up. They want up-to-date information related to their child's condition, and they want care that encompasses the full spectrum of their child's needs, including mental and behavioral health, not just a single bodily system or condition. They want care that supports the transition to adulthood and prepares them for the future. They want an approach to communication that respects their cultural and linguistic heritage, including their religious beliefs. These family survey data also show that the care that CYSHCN now receive falls far short of what is desired. For example, using the National Survey of Children with Special Healthcare Needs (2005-2006), 23% of parents reported being unable to get key family support services, and 33% reported not receiving family-centered care.15

MODEL SYSTEMS FOR CHRONIC ILLNESS CARE AND PREVENTION

The high cost and poor outcomes of care for adults and children with chronic conditions have led to the development of new models for the delivery of care, models that build on the basic framework of primary care with significant modifications to address the shortcomings noted above. The most prominent of these is the "chronic care model" developed by Ed Wagner and later adapted for child health in a medical home by the National Initiative for Children's Healthcare Quality (NichQ) and the Center for Medical Home Improvement for the first national Medical Home Learning Collaborative 16 (see Figure, page 484).

The Care Model assumes that care is best delivered by a healthcare team rather than by a single individual. Recognizing that patients and families manage most aspects of care most of the time, the Care Model emphasizes the need of patients and families for sufficient knowledge, skills, and motivation to manage their healthcare effectively. Healthcare practices and systems must draw on community resources to help patients achieve better outcomes.17

This model specifies particular practice systems that enable the delivery of effective care. These include clinical information systems that are able to note which patients in a practice have specific clinical conditions, the severity or complexity of those conditions, and other information relevant to patient and population management. Another system element is the use of planned visits — scheduled encounters during which matters of importance can be thoughtfully reviewed and future approaches developed. Written care plans can become the script and the record of such planned visits, particularly when the joint development of these plans with families is aimed toward achieving mutually set goals. Mechanisms must also be established to obtain specialist expertise and integrate that expertise into an explicit comprehensive approach to care.

A recent systematic review of the elements of the medical home for CYSHCN showed that children who receive care in settings that demonstrate elements of the medical home have better short-term outcomes than children who do not.18 Coolen et al demonstrated that practices with higher Medical Home Index scores had significantly lower hospitalization rates for children with chronic conditions.19 McAllister et al found that families of CYSHCN perceived their child to be healthier and experienced less worry when they received care in a medical home.20

AN INTEGRATED VISION: THE FAMILY-CENTERED MEDICAL HOME

Recently, the family-centered medical home (often referred to as the patient-centered medical home in the adult health community) has emerged as an integrative systems model incorporating the principles of the chronic care model and the work of primary care health system architects. Coined in 1967 in an American Academy of Pediatrics (AAP) proposal for centralized medical records, "medical home" has evolved to become a new brand name for redesigned primary care. Initial work defining and expanding the medical home idea began in the early 1990s when Calvin Sia piloted enhanced communication and coordination of services between Hawaii's primary care pediatrics and local early intervention programs serving young children with special healthcare needs. Dr. Sia partnered with Merle McPherson of the U.S. Maternal and Child Health Bureau (MCHB) to develop leadership at the AAP in the further refinement and implementation of the medical home model as high quality primary care for children and youth with special healthcare needs. Through national U.S. MCHB demonstration projects between 1996 and 2008 and with the establish-
In 2003, with funding from U.S. MCHB, the National Initiative for Children’s Healthcare Quality (NICHQ) partnered with CMHI to conduct the first national medical home learning collaborative. With 11 states and more than 30 pediatric practices participating, this learning collaborative demonstrated that pediatric practices could combine quality improvement methods with consumer participation and collaboration with state Title V programs to introduce sustainable changes resulting in better outcomes for CYSHCN (eg, reduced emergency department visits). This program, together with a second year-long learning collaborative, provided the nucleus for policies and projects supporting further spread of the medical home model in a number of the participating states. However, widespread expansion of the medical home model beyond the early adopters in pediatrics has remained limited by the absence of reasonable financial incentives for practices to change.

The confluence of several trends in 2004 transformed the medical home movement from a small stream in children’s healthcare to a raging cataract coursing across the landscape of health reform. This confluence began in May 2004 when the American Academy of Family Physicians published “The Future of Family Medicine,” in which the primary care medical home occupied a central role. Within 2 years, the American College of Physicians described the Advanced Medical Home as a tiered and measurable model of adult primary care that could be coupled with new prospective reimbursement strategies, which might not only cause change but also revitalize adult primary care as a more attractive career option for young physicians in training. Medical home had expanded from a child health focus to a lifespan-spanning model, including the potentially large financial leverage associated with improving the efficiency and quality of care for millions of adults and seniors.

In fall 2006, large corporate purchasers of healthcare partnered with representatives of the major primary care professional organizations, major private health insurers, representatives of the National Committee on Quality Assurance (NCQA), various consumer organizations, and other industry groups to formulate a common vision of transformed primary care. From these discussions, the Patient-centered Primary Care Collaborative (PCPCC) was born and continues to monitor and motivate conversations and political action helping to ignite a national awareness of the medical home.

The four primary healthcare professional organizations crafted and endorsed a pivotal agreement on medical home principles published in spring 2007 as the “Joint Statement of the Patient-centered Medical Home.” This document emphasizes an ongoing relationship with a personal primary care provider who leads an accessible practice team applying a whole-person approach to coordinated and integrated care. The joint statement advocates for a payment structure that “recognizes the added value” of a patient or family-centered medical home. All that remained was a framework for sustainable payment and a method for determining which practices should benefit from new payment scenarios.

Fueled by PCPCC activities and the primary care professional organizations, the nation’s largest private insurers began to discuss medical home pilot projects mostly focused on adult healthcare. By early 2008, a number of these single and multi-payer medical home pilots were getting underway. These pilot programs used newly published NCQA Physician Practice Connection Patient-centered Medical Home recognition criteria to qualify practices as medical homes and provided prospective per-member, per-month supplements to usual and customary fee for service reimbursement. These health plan-initiated pilot proj.
included a variety of evaluation models intended to study both quality and utilization outcomes, although increased efficiency (ie, reduced costs) will be essential for the plans to provide sustained and systematic support.

In the event of favorable results from the various private plan medical home pilot projects, more complex incentive models are likely to emerge. Many of these would include a hybrid combination of traditional fee-for-service reimbursement with prospective, capitated administrative, or care coordination payments and quality or pay-for-performance incentives based on meeting specific performance incentives. Driven by 2006 federal legislation, the Centers for Medicare and Medicaid Services (CMS) is planning to roll out a medical home demonstration project in 2010 for eight states. These projects will share savings with participating practices in addition to providing capitated payments. A number of state Medicaid programs are also considering medical home projects.

In summer 2008, the National Academy of State Health Policy (NASHP) convened teams from eight states working on medical home projects and policies. In 2009, the Commonwealth Fund has launched a national demonstration project applying the medical home model in "safety net" clinics, including federally-qualified community health centers.

CONTROVERSIES AND AMBIGUITIES

Although the medical home movement has gained speed and intensity, it has not paused to address several areas of ambiguity, both in the broad world of healthcare across the age span and specifically related to the care of children and youth with special healthcare needs. The relative role of individual physician-managed versus team-based care remains ambiguous, as does the role of other types of primary care clinicians (eg, nurse practitioners and physician assistants). Mechanisms for small practices with limited personnel or management capability to undertake care coordination and population management are still under development. Although the pediatric medical home model advocates for the central involvement of families in promoting and sustaining practice transformation, this level of patient engagement has been largely absent from adult models.

The suitability of the primary care medical home as the locus of care for the child with complex special healthcare needs has also been challenged by parents, specialists, and even primary care clinicians. Parents of children with rare conditions, such as genetic or inborn errors of metabolism, whose treatment base is rapidly evolving, or who use multiple specialists, report their primary care clinician is often understandably neither conversant with the latest technical knowledge nor able to devote appropriate time to assist with management and coordination. For the majority of children, including most CYSHCN, all of the elements of the medical home are best provided in a community-based, primary care practice, particularly if those practices are provided with improved support to undertake this function. For some children and youth with complex healthcare needs and ready access to specialty services, some or all of the responsibilities of the medical home may lie with a specialty or hospital-based program (eg, a comprehensive sickle cell program or hospital-based "coordinated care" service). For children whose medical home is in the specialty setting, the primary care site may be considered the specialist in preventive care, although no longer fulfilling the comprehensive element of the primary care definition. Regardless of the locale of each child's medical home, explicit arrangements and agreements between providers will be needed to assure that these functions (including preventive care and care addressing broad family needs) are fulfilled. This can be achieved with effective care coordination and improved communication.

CRITICAL INGREDIENTS FOR MEDICAL HOME TRANSFORMATION

The MHI and the NCQA Physician Practice Connection—Patient-centered Medical Home recognition award emphasizes the structures and processes of care needed for a practice to be a medical home. The elements these tools catalogue may catalyze or enrich the transformation and implementation process.

Family Involvement

Families are the true consumers of child healthcare. Parents or their surrogates make choices about where, when, and how to access care for their children until the children reach 18 years (or longer, in the case of youth with disabilities whose parents or others have guardianship status). The choices that families make about healthcare are based on many factors, including distance, time of day, costs, and their perceptions of quality of care. These choices affect the quality and cost of the care for children in the community or region. As a result, practices and primary care networks considering medical home transformation or other efforts to improve care cannot be effective without engaging the families and youth who utilize their services. The involvement of families in quality improvement and change is an extension of family-centered practices at the level of individual clinical encounters in which families or patients are considered a part of the care team sharing a stake in the outcomes of care decisions. Through family advocacy organizations such as Family Voices, these local practice level partnerships with families around clinical care and quality improvement have been extended to the involvement of families in policy and legislative activities related to the availability and support of high quality primary care for children.
Quality Improvement and Accountability

Linking payment to achieving a level of “medical home-ness” requires the use of measures of medical home (already described) and accountability for achieving such levels of implementation. This static measurement of accountability, although necessary and potentially useful in providing motivation, doesn’t reflect a second element of well-functioning medical homes — the capacity for continuous improvement. Medical homes use data (typically from the health information systems described below, as well as from families and staff) to assess current performance and then use process improvement (such as the model for improvement) to change practice processes and systems to achieve better results. Such approaches typically are team-based, and often benefit from benchmarking across multiple settings to accelerate the process of learning.

Care Coordination

Care coordination is one of the signature services of a primary care medical home. Care coordination facilitates access and appropriate decision-making for patients and families while tracking the results of healthcare encounters, including laboratory tests, x-rays, specialty visits, and hospitalizations. Care coordination is the mechanism through which care planning and implementation flow before, during, and after office visits. Pre-visit contacts may collect new health information and current patient or family concerns to inform an upcoming chronic condition management office visit, whereas post-visit contacts can confirm follow-through and full understanding of decisions made during the visit. Care coordination as a set of activities may be explicitly distributed among various members of the healthcare team. Families, particularly those of children with complex healthcare needs, may have care, case, or service managers associated with a variety of systems involved in their child’s needs (healthcare, special education, mental health, visiting nurses, managed care organizations, etc.), and they may find themselves responsible and provide greater power. Electronic registries, even those using simple electronic spreadsheets, afford the potential to monitor use of medication and laboratory tests and to monitor trends and results. These components have led the NCQA measure of the patient-centered medical home to heavily weight these elements of health information technology (registries, e-prescribing).

Health Information Technology

Health information technology can facilitate many key functions of the medical home. In order to manage the care of both individuals and a population, a medical home must be able to aggregate the children with a special condition or of a specific age or condition complexity, to identify outcomes, presence, or absence of needed services, and track over time. Although some tracking can be done using paper-based systems, electronic registries make this task far easier and provide greater power. Electronic registries, even those using simple electronic spreadsheets, afford the potential to monitor use of medication and laboratory tests and to monitor trends and results. These components have led the NCQA measure of the patient-centered medical home to heavily weight these elements of health information technology (registries, e-prescribing).

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for coordinating the coordinators. Each system requires a locus of coordination to manage the elements within that system and to interface with coordination counterparts in other systems.
STATE AND FEDERAL POLICY

State and federal policies are accelerating the adoption of the family-centered medical home. Bright Futures Guidelines for Children and Adolescents, developed by the AAP with support from HRSA's Maternal and Child Health Bureau, promotes medical home as the standard of care for all children.25 The Healthy People 2010 objectives for the nation specifically establishes the medical home as a goal for children with special healthcare needs.26

Medical home initiatives now exist in all states and are funded and supported through multiple national public and private entities. For example, HRSA's Maternal and Child Health Bureau supports the pediatric medical home through the National Center for Medical Home Implementation at the AAP, medical home demonstration projects in more than half of the states, and quality improvement work on medical home implementation. Multiple other national organizations, both public and private, support medical home demonstration activities, including CMS; the National Association for State Health Policy (NASHP); PCPCC; the Commonwealth Fund; and numerous health plans. The recent expansion of the Children's Health Insurance Program (CHIP) to provide coverage for children is a major step toward extending medical home to all children. Research shows that children without insurance are far less likely to have a medical home than insured children.27 However, simply extending existing coverage to more children will not achieve the vision of medical home. Healthcare benefits and reimbursement structures must provide incentives for coordinated, comprehensive care, including prevention and chronic care management.

Improving partnership with families and consumers at all levels of practice, program, and policy can reap significant benefits.28 To support this partnership, the Family Opportunity Act (FOA) establishes Family-to-Family Health Information Centers in every state and the District of Columbia. These centers, run by family/consumer organizations, are intended to support families, provide information and foster partnerships and shared decision-making with healthcare professionals. Entities such as Family Voices and Parent-to-Parent exist in every state to support this partnership. The National Partnership for Women and Families has emerged as a strong advocate for the Patient Centered Medical Home as a way of driving health system reform.

Two national surveys, the National Survey of Children's Health (NSCH) and the National Survey of Children with Special Healthcare Needs (NSCHN), provide national and state level estimates of medical home implementation for children. Both surveys indicate that about half of children currently have access to a medical home.29 These measures confirm that although most children have a usual source of care, far fewer have care that provides for needed care coordination, assures access to needed referrals, and provides care that is family-centered.

Implementing the medical home depends on the entire healthcare team, physicians, nurses, physician's assistants, and practice managers. Current provider shortages in primary and specialty care have resulted in long waiting lists and limited access to care. Assuring comprehensive care also presents a major challenge for healthcare professionals inadequately trained to provide care in the context of a medical home and inadequately reimbursed to create the practice structures needed to serve in this capacity. To assure medical home implementation, not only must an adequate supply and distribution of health professionals training programs be achieved, but curricula must be redesigned to include skills to prepare providers to coordinate and integrate care across traditional organizational and disciplinary boundaries.

These national and state initiatives differ significantly depending on the population addressed. Some focus on chronic condition management, while others focus on prevention. Some focus on children, while others focus primarily on adults. At the macro level, the principles of medical home are common across the life span. But at the policy, program, and practice level, these principles manifest differently for children and adults. For policymakers concerned with healthcare for children, the challenge is to build upon the collective efforts of current initiatives, synthesize the best practices currently being demonstrated for children, develop health policy that is coherent, comprehensive and evidence-based; and identify strategies for promoting universal, equitable, and sustainable implementation of the medical home for all children, youth, and their families.

CONCLUSION

Many observers and influential policymakers now see a reinvestment in primary care and a reformulation of that care along the model of the medical home as essential to improving the performance of our healthcare system and not only the care of children with special healthcare needs. Key elements of the model include team-based care, care coordination, population monitoring, and use of quality improvement. Successful practice transformation will require expanded use of health information technology and realignment of financial incentives along with practice-level technical assistance and coaching. Those in child health believe that involvement of patients and families in the transformation process is essential to success. Federal and state policies promoting use of health information technology, realigning incentives, providing training, and monitoring successful implementation are already under way, and will need expansion and coordination to
have maximum effect. All children stand to benefit from this effort. Our task is make sure that the system is appropriately designed to meet the unique needs of this population, including the needs of the population for whom the model was first proposed—children and youth with special healthcare needs.

REFERENCES
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