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History of the Medical Home Concept

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ABBREVIATIONS. AAP, American Academy of Pediatrics; CSHCN, children with special health care needs; COPP, Council on Pediatric Practice; BOD, Board of Directors; MCHB, Maternal and Child Health Bureau; SPRANS, Special Projects of Regional and National Significance; CATCH, Community Access to Child Health.

“Every child deserves a medical home” is one of the American Academy of Pediatrics’ (AAP) essential child health outcomes for the 21st century. With increasing health care costs, technology, survivorship, specialization, and fragmentation of care, the medical home is steadily gaining interest and standing in the public eye. Today’s policy makers, those who are involved with children, and parents are increasingly using the term to describe the concept as the form of high-quality health care. With so much attention focused on this concept as the standard of care for all infants, children, adolescents, young adults, and particularly children with special health care needs (CSHCN), it is important to define this term and how its definition has evolved. Whereas the term was originally used to describe a place—a single source of all medical information about a patient—the term now refers to a partnership approach with families to provide primary health care that is accessible, family centered, coordinated, comprehensive, continuous, compassionate, and culturally effective.¹

PRELUDE: 1960s TO 1970s

The first known documentation of the term “medical home” appeared in *Standards of Child Health Care*, a book published by the AAP in 1967 and written by the AAP Council on Pediatric Practice (COPP). The book defines a medical home as one central source of a child’s pediatric records and emphasizes the importance of centralized medical records to CSHCN. “For children with chronic diseases or disabling conditions, the lack of a complete record and a ‘medical home’ is a major deterrent to adequate health supervision. Wherever the child is

cared for, the question should be asked, ‘Where is the child’s medical home?’ and any pertinent information should be transmitted to that place” (pp 77-79).²

The COPP, noting that care for CSHCN is often provided by many different practitioners who work in disparate locations independent of each other, was concerned about the duplication and gaps in services that occur as a result of this lack of communication and coordination. To resolve these problems, the COPP advocated for 3 steps to spread the word about the importance of the medical home: “The first requirement is the teaching of all medical students that a medical home and a complete central record of a child’s medical care are the sine qua non of proper pediatric supervision. Second, the concept must spread from physicians to all agencies and people caring for children—schools, child guidance clinics, well-infant stations, surgical specialists, emergency departments, and so forth. The third step is the indoctrination of parents (pp 78-79).”³

Although *Standards of Child Health Care* was, at the time it was published, an important guide for pediatric practice, it did not define AAP policy. It was not until the 1970s that the AAP began to address the policy implications of the term “medical home.”

In 1974, the COPP held a meeting to begin developing a policy statement titled “Fragmentation of Health Care Services for Children.” The COPP noted that the “delays, gaps, duplications, and diffused responsibilities which characterize fragmented care are expensive, inefficient, and sometimes hazardous to health” and that “implicit in these [the AAP constitution’s] standards is a commitment to the principle that each child deserves a ‘medical home.’”³ The draft policy statement called for centralization of medical records and for pediatricians to become advocates for their patients so that they may receive continuous care, without financial or social barriers. Later, it was added that “the term ‘medical home’ should replace the term ‘family physician,’ ‘pediatrician,’ or ‘personal physician,’ and like terms on all questionnaires and forms requesting identification of the source of continuing child health care.”⁴

These versions of the statement were initially rejected by the AAP Board of Directors (BOD) on the grounds that the BOD believed that it could not determine terminology to that degree. Later, the BOD revisited the statement, recognizing that the intent of the statement was to clarify for third parties the concept of a single medical home for every child. In 1977, the statement was published with the following reference to medical home: “Quality medical

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care is also best provided when all the child's medical data are together in one place, (a medical home) readily accessible to the responsible physician or physicians."⁵ In April 1979, the importance of the medical home—defined as the repository for medical records, in a manner ensuring continuity of care—was reiterated in the policy statement "Children Having Care from Multiple Sources."⁶

Health Care Home Versus Medical Home

All AAP chapter presidents were asked to create a child health plan for their respective chapters. In 1978-1979 in North Carolina, there were efforts to provide what they called a medical home to all children through a "Child Health Planning" process. According to Dr Steve Edwards, the North Carolina chapter president was "shot down" by state legislators who were concerned that pediatricians were taking over too much of the parents' responsibility. The state legislators did not, at the time, understand the meaning of the term "medical home," and they misunderstood the intentions of the pediatricians. Consequently, the concept was no longer used in North Carolina chapter's child health plan discussions. Although the legislation was never approved, the drafts referred to children having a "health care home" with the following characteristics: 1) commitment to the individual, 2) primary services, 3) full-time accessibility, 4) service continuity, 5) comprehensive record-keeping, 6) competent medical management, and 7) cost-effective care. The responsibilities of the child and the family in the health care home were defined as 1) continued acceptance and contact, 2) conformance with recommendations of prevention and promotion, 3) adequate information flow, and 4) compliance with administrative requirements.

The North Carolina Child Health Plan did not advocate for a single organizational model for the health care home but rather recommended a combination of private, public, and joint ventures that best meet the needs of all of the children in a community. Again, this draft legislation was never approved, but the discussions that led to the development of the draft reflect the changing meaning of the medical home.

Nationally, the medical home concept began to evolve from a centralized medical record to a method of providing primary care from a community level, recognizing the importance of addressing the needs of the total child and family in relationship to health, education, family support, and the social environment. The concept assumed a bottom-up, or grassroots, approach rather than a top-down approach and shifted toward prevention, wellness, and early intervention. This concept initiated an approach toward developing a single-tiered system of care, especially for CSHCN.

FOCUS ON PRIMARY CARE: HAWAII IN THE 1980s

Concerned about the initiatives that lacked the primary care component, Merle McPherson, MD, director of the federal Maternal and Child Health Bureau's (MCHB) Division of Services for Children

with Special Health Care Needs, took note of an approach that was developed and championed in the 1980s by Dr Calvin Sia in Hawaii. A continuous system of care for CSHCN that originates in the pediatrician's office and involves an inherent partnership between the parent and the primary care pediatrician was provided. This system, with the primary care pediatrician (who is geographically and financially accessible) as the point of first contact for the child and family, enabled families to receive continuous and comprehensive care and ensured that there was linkage to all medical and nonmedical services and resources from infancy through adolescence.

Legislative Initiatives

In 1978-1979, Hawaii under Dr Sia's leadership, unlike North Carolina, successfully led a campaign to have the medical home concept adopted into their Child Health Plan that stated, "Every child deserves a medical home." This campaign required a year of persistent effort by representatives from the Hawaii chapter, the University of Hawaii John A. Burns School of Medicine Department of Pediatrics at Kapi'olani Medical Center for Women and Children, the Hawaii Department of Health, and the Hawaii Medical Association. This was the birth of the medical home concept as we know it today. It stated that a medical home would be family centered; be community based (geographically and financially accessible and available); offer continuity, comprehensive, and coordinated care; and use the resources of related services in the neighborhood.

Five years later, in 1984, the medical home concept was implemented through the Hawaii Healthy Start Home Visiting Program for the prevention of child abuse and neglect. The following year, in 1985, the concept was integrated into the Hawaii Emergency Medical Services for Children Program by ensuring that children and families, as part of the medical home, were the central point of the system.⁷ In the same year, the Hawaii Medical Association was awarded a grant from MCHB, under the Special Projects of Regional and National Significance (SPRANS) initiative, to train primary care physicians to become a medical home for CSHCN. Finally, in 1986, the Hawaii Early Intervention Program under PL 99-457 Part H: Individuals With Disabilities Education Act Amendment of 1986 for infants and toddlers was launched to include the medical home into each discipline: family support, health, and education.

Overcoming Barriers to the Medical Home

Nationally, as the medical home concept evolved and gained greater recognition, barriers to implementing a medical home for all children became apparent. Three major barriers⁸ in implementing the concept were 1) training pediatricians to understand the medical home concept; 2) communication and care coordination for related services in health, family support, and education/special education; and 3) reimbursement for periodic well-child supervision and care coordination.

In Hawaii, a federal SPRANS grant enabled the Hawaii Medical Association to overcome the first of these barriers by developing a medical home training manual that involved interdisciplinary teamwork and that brought pediatricians together with families and related child health care professionals. The training addressed the communication and care coordination barriers between individuals and agencies by suggesting the Hawaii's Healthy Start home visitors act as links to the medical home. At the same time, Healthy Start and the Hawaii's Early Intervention Program were strategically placed within the Hawaii Department of Health rather than in the Department of Education, which was the experience of most states. The Hawaii Early Intervention Program provided the leadership for the enactment of a state law (Act 109) that created support for all families with children who had developmental delays, were biologically at risk, and especially who were environmentally at risk. Public health nursing played a major role in this evolving system of care. The reimbursement barrier was addressed by introducing into the Hawaii State Legislature an increased budget for Early and Periodic Screening, Diagnosis, and Treatment (under Medicaid) and a mandated Well Child Health Supervision bill. Additional support for families and early intervention providers was requested for Hawaii's Early Intervention Program. Introducing family advocates and including them in the planning process was an important key in the legislative successes.

SPREADING THE WORD THROUGHOUT THE NATION: LATE 1980s TO 1990s

As part of the MCHB SPRANS grant in Hawaii, leadership from the project traveled nationally to promote the medical home concept. In 1987, Surgeon General Koop held the first major conference for CSHCN. In 1989, the first AAP conference on the medical home was held in Hawaii. This conference was followed by consultation to introduce the medical home training program to interdisciplinary teams of pediatricians, families, and other health care-related professionals in Florida, Minnesota, Nebraska, Pennsylvania, Washington, and other states. These significant events set the foundation for the developments that occurred in the 1990s when the AAP and MCHB assumed a more direct role in the refinement and implementation of the medical home concept.

In 1992, the AAP published its first policy statement defining the medical home: The AAP believes that the medical care of infants, children, and adolescents ideally should be accessible, continuous, comprehensive, family centered, coordinated, and compassionate. It should be delivered or directed by well-trained physicians who are able to manage or facilitate essentially all aspects of pediatric care. The physician should be known to the child and family and should be able to develop a relationship of mutual responsibility and trust with them. These characteristics define the "medical home" and describe the care that has traditionally been provided by pediatricians in an office setting. In contrast, care pro-

vided through emergency departments, walk-in clinics, and other urgent-care facilities is often less effective and more costly.⁷

By 1993, the AAP established a Division of Community Pediatrics in support of its flagship program Community Access to Child Health (CATCH) that embraces at its core the medical home concept. CATCH promoted the vision that every child in every community has a medical home and other needed services to reach optimal health and well-being; that pediatricians can make a difference in their community. Through the efforts of dedicated CATCH pediatricians, access to child health care and the medical home concept became a reality to many. The CATCH program developed a network of pediatricians and a groundswell of support from families and communities promoting improved child health care not only for CSHCN but for all children.

The second major program of the Division of Community Pediatrics was the medical home Training Project, a national adaptation of the Hawaii Medical Home Project. From 1994 through 1999, the AAP received a grant from MCHB that enabled the continuation of this project into what became known as the Medical Home Program for Children With Special Needs. The Medical Home Program for Children With Special Needs produced materials to educate pediatricians, parents, and other health care professionals nationwide about the medical home concept. Among the materials produced were a fact sheet describing the concept in lay terms, a compendium of information about the medical home and managed care, a guide for appropriate use of Current Procedural Terminology codes to improve reimbursement for provided services, a pamphlet on the importance of early intervention, and an updated version of The Medical Home Training Program.⁹

Thus, the Medical Home Project has been closely linked to the CATCH network.⁹ As the interest in community pediatrics increased, the AAP Division of Community Pediatrics expanded to become a Department of Pediatrics. The Department has promoted major national efforts such as Breastfeeding Promotion in Physicians' Office Practices, Childhood Immunization Support Program, Healthy Child Care America, Healthy Tomorrows Partnership for Children Program, Medical Home Initiatives for Children With Special Needs, Screening Initiatives, Native American Child Health, Pediatrics Collaborative Care Program: Oral and Mental Health Initiatives, and Reaching Children: Building Systems of Care. This has helped ensure widespread dissemination of the medical home concept and application of this concept to all children, not only CSHCN.

AAP National Center

In 1999, the MCHB grant ended and the AAP Department of Community Pediatrics was awarded a 5-year cooperative agreement with MCHB to establish and operate the National Center of Medical Home Initiatives for Children With Special Needs (National Center). Nearly all of the materials and resources developed by the National Center, including links to medical home activities in other states,

can be accessed through the comprehensive web site at www.medicalhomeinfo.org. The goals of the National Center are to

1. Contribute to changes in and influence the development of policies to establish medical homes for all CSHCN
2. Increase knowledge and skills among health care professionals who care for CSHCN
3. Analyze, compile, and disseminate outcomes of medical home
4. Develop and sustain a national technical assistance program

The National Center provides support to pediatricians, families, and other medical and nonmedical providers who care for CSHCN. Specifically, parents, pediatricians, administrators, and other health care professionals have access to educational and advocacy materials, screening tools, guidelines for care, and a national medical home mentorship program.

Most important, in 2002, the AAP, in consortium with the National Center's Project Advisory Committee, published the policy statement "The Medical Home." This statement expanded on the definition of medical home described in the original 1992 policy statement. The 2002 policy statement retains the original 7 components of a medical home (accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective) and describes the services that should be provided within this framework. The 2002 statement continued to explain further the medical home model of care by providing an operational definition that lists 37 specific activities that should occur within a medical home.

AAP Medical Home Training Program

Partnerships are an important component of the medical home concept and are essential to ensuring that systems of care are coordinated. With this principle in mind, the National Center partnered with Family Voices, Shriners Hospitals for Children, and the National Association of Children's Hospitals and Related Institutions to develop an updated and more comprehensive version of the Medical Home Training Program that was originally developed through the Hawaii SPRANS grant. This collaboration continues today, as each partner ensures that its members and colleagues are active participants wherever the training program is implemented.

The AAP Medical Home Training Program focuses on how to ensure that CSHCN have a medical home.¹ The program offers several educational components, including practical strategies for improving practices, integrating screening activities, coordinating systems of care, advocating for patients and families, and transitioning youths with special health care needs to work and independence. Each of these components is presented within the context of family-professional partnerships in a medical home. The curriculum has been written so that the materials can be easily customized to incorporate local information and address the community's current health care environment.

Medical Home Mentorship Network

Although the National Center continues to provide technical assistance to individuals who are trying to create medical homes, it was soon recognized that this effort could go only so far. It was determined that individuals required a more structured system in place at the state level to support their community- or practice-based initiatives. As a result, the National Center called on key stakeholders to build a medical home team to lead their state in developing policies to support the creation of medical homes. Each state team (consisting of pediatricians, family physicians, a CATCH pediatrician, families, Title V CSHCN directors, and other key leadership in the state) wrote a "Promise to the State" that outlined their vision for a coordinated system of care for CSHCN that would provide 100% access to medical homes by the year 2010. As the National Center continues to facilitate the development of these teams nationwide, state teams that have demonstrated exceptional progress toward their goals have been named as mentors to guide new state teams in their work toward achieving their medical home plans. Currently 15 states have received funding from the MCHB to implement these state medical home plans.

Screening and the Medical Home

Screening is the first step in identifying a child who has special health care needs. Therefore, it is important that early and continuous screening is incorporated in the medical home to ensure that 1) children with undiagnosed special health care needs are identified as early as possible so that they and their families can be given appropriate services to address those needs and 2) children with existing special health care needs receive continuous screening and surveillance to identify or prevent secondary conditions that may interfere with their development and well-being.

Staff at the National Center have engaged in projects to ensure that screening is integrated appropriately in the medical home. Some projects have related specifically to population-based public health screening (eg, newborn metabolic/genetic screening, newborn hearing screening), whereas others have related to medical home-based screening (eg, preschool vision screening, developmental screening).

FUTURE DIRECTIONS

Ensuring that all children in the United States have a medical home has been the challenge of the latter half of the 20th century and the beginning of the 21st century. Although this goal has not yet been achieved, efforts to ensure that all children worldwide have a medical home have continued. In the late 1990s, the AAP, the MCHB, Family Voices, and other agencies and organizations began to examine the progress made toward achievement of the surgeon general's Healthy People 2000 objective that called for implementing a family-centered, community-based system of services for all children in the United States. Although much progress has been

made, CSHCN still face many obstacles in obtaining comprehensive, coordinated, and family-centered health care.

The challenges to overcoming these obstacles are being envisioned by key stakeholders, who will inspire supportive services, craft compelling policies, and develop medical home competencies within pediatric residency programs toward the development of a future pediatric workforce. Key to the success of integrating the medical home in systems of care are federal policy makers such as the MCHB, the National Institute of Child Health and Human Development, and the Centers for Disease Control and Prevention National Center for Birth Defects and Developmental Disabilities; major pediatric organizations, such as the American Board of Pediatrics, the Pediatric Academic Societies, and the AAP; and private foundations, such as the Dyson Foundation, which supports the Anne E. Dyson Community Pediatrics Residency Training Initiative. Important stakeholders such as these share in the vision to create a new generation of pediatricians who can build on trusting family-pediatric partnerships that ultimately benefit all children and families.

National Pediatric Workforce Initiatives—Task Force for the Future of Pediatric Education

As the medical home concept was being integrated into federal policies that address systems of health care, all of the major pediatric organizations' representatives met in 1997 to discuss and study pediatric workforce issues and the future of pediatric education. By January 2000, the Task Force on the Future of Pediatric Education issued its recommendations. Two relevant recommendations were that "all children should receive primary care services through a consistent Medical Home, and . . . pediatric medical education at all levels must be based on the health needs of children in the context of the family and community."¹⁰

Private Partnership Initiatives—Anne E. Dyson Community Pediatrics Residency Training Initiatives

Bold private initiatives, such as the Anne E. Dyson Community Pediatrics Training Initiative of 2000, offered funding to medical schools to teach pediatric residents new skills and encourage a new attitude about community pediatrics, in effect encouraging residents to ensure that they were providing medical homes. Since July 2002, 10 medical schools' pediatrics residency programs have received funding. A few of these grantees are using this opportunity to allow the medical home concept to serve as the "base" or core foundation for pediatric residency training in community pediatrics.

New Visions From a New Administration: New Freedom Initiative—Delivering on the Promise

One of the objectives for Healthy People 2010 states that children with special health care needs will receive ongoing, comprehensive care within a medical home. In March 2002, Health and Human Services Secretary Tommy G. Thompson presented to President Bush reports from 9 federal agencies

outlining many specific solutions to implement support for those with disabilities within the New Freedom Initiative—Delivering on the Promise. Among the recommendations was that the MCHB take the lead in developing and implementing a plan to achieve appropriate community-based services systems for children and youths with special health care needs and their families. Components of the plan include

1. Development of community-based systems of services that are inclusive of CSHCN and their families, where substantial decision-making authority is devolved from the federal government to the states to the communities.
2. Recognition that families are the ultimate decision makers for their children and encouragement of participation in making informed decisions.
3. Development of standardized elements of the medical home for CSHCN. In addition, the agency will develop and disseminate models of the medical home and provide additional training resources to primary care professionals to develop medical homes.
4. Review of the variety of reimbursement mechanisms that affect CSHCN.
5. Through the MCHB block grant (Title V of the Social Security Act) and the Newborn Genetics Program (Title XXVI of the Child Health Act), expansion and strengthening of newborn screening systems and promoting ongoing screening of CSHCN (incorporating Early and Periodic Screening, Diagnosis, and Treatment in the medical home concept).
6. Ensuring that youths with special health care needs receive transition services to all aspects of adulthood, including from pediatric to adult health care from school to employment and independence.

CONCLUSION

The development and implementation of the medical home concept has received tremendous support from the MCHB, the federal lead agency; the AAP, through policies and programs; the Pediatric Academic Societies; and national and state family organizations. As pediatricians across the United States increasingly adhere to the highest standards of care by ensuring in partnership with families that all children have access to a medical home, 1 of the essential AAP child health outcomes of the 21st century is closer to being achieved. In moving from medical home as a concept to medical home as an implemented quality health care strategy, every child in the near future will indeed have a central source of health care that is family centered, accessible, continuous, coordinated, comprehensive, compassionate, and culturally effective.

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