A Retrospective Look at Programs and Initiatives Toward a Family-Centered Medical Home for Every Child and Youth

2008-2013
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ACKNOWLEDGMENTS

Medical Home Implementation Project Advisory Committee 2012–2013
Calvin Sia, MD, FAAP (Co-chairperson)
William Carl Cooley, MD, FAAP (Co-chairperson)
Richard Antonelli, MD, MS, FAAP
Bruce Bagley, MD
Beverly Johnson
Thomas Klitzner, MD, PhD, FAAP
Jennifer Lail, MD, FAAP
Linda Lindeke, PhD, RN, CNP
Lee Partridge
William Schwab, MD
Christopher Stille, MD, MPH, FAAP
Debra Waldron, MD, MPH, FAAP
Nora Wells, MSED
Colleen Kraft, MD, FAAP (liaison from the AAP Council on Community Pediatrics)
Thomas Long, MD, FAAP (liaison from the AAP Committee on Child Health Financing)
Marie Mann, MD, MPH, FAAP (Maternal and Child Health Bureau)

Past Project Advisory Committee Members and Liaisons 2008-2012
Timothy A Geleske MD, FAAP
Chris Olson, MD, MHPA, FAAP
Gina Pola-Money
Phyllis Sloyer, PhD, RN
Nancy Swigonski MD, FAAP
Brad Thompson, MA
Steven Wegner MD, JD, FAAP

National Center Staff
Fan Tait, MD, FAAP
Michelle Zajac Esquivel, MPH
Elsa Hall
Stephanie Mucha, MPH
Angela Tobin, AM, LSW

“Being part of the advisory panel has been an important experience for us, as it has given us a much deeper understanding of the challenges and needs of the pediatric community in order to continue its leadership in providing patient-centered care. It is also a pleasure to work with such a solid professional staff!”

–Lee Partridge, Senior Health Policy Advisor, National Partnership for Women and Families

The National Center of Medical Home Implementation is funded, through a cooperative agreement, by the Maternal and Child Health Bureau (“Medical Home Capacity Building for CSHCN” [grant number U43MC09134]).
A family-centered medical home is not a building, house, hospital, or home health care service, but rather an approach to providing accessible, continuous, comprehensive, patient- and family-centered, coordinated, compassionate, and culturally effective primary care to all children and youth, including those with special health care needs. Receiving coordinated, ongoing, comprehensive care within a medical home is one of the six core health indicators of progress identified by the federal Maternal and Child Health Bureau (MCHB) towards the goal of promoting a community-based system of services mandated for all children with special health care needs.

In a pediatric family-centered medical home, a pediatric care team works in partnership with a child and his or her family to assure that all of the patient’s medical and nonmedical needs are met. Through this partnership, the team helps the patient and family access, coordinate, and understand specialty care, educational services, out-of-home care, family support services, and other public and private community services that are important for the overall health of the child and family.

The American Academy of Pediatrics (AAP) believes that everyone deserves a medical home, and other primary care medical organizations agree. In March 2007, the AAP was joined by the American Academy of Family Physicians, the American College of Physicians, and the American Osteopathic Association in publishing “Joint Principles of the Patient-Centered Medical Home.” This consensus statement described seven principles of a medical home: personal physician, physician-directed medical practice, whole-person orientation, coordinated care, quality and safety, enhanced access, and appropriate payment.

Caring for children and youth—those with and without special health care needs—and their families presents unique challenges and opportunities. The pediatric family-centered medical home embraces special features:

- **Patient- and family-centered partnership**: A medical home provides patient- and family-centered care through a trusting, collaborative, working partnership with families, respecting their diversity and recognizing that they are the constant in a child's life.

- **Community-based system**: The medical home is an integral part of the community-based system, a patient- and family-centered coordinated network of community-based services designed to promote the healthy development and well-being of children and their families. As such, the medical home works with a coordinated team, provides ongoing primary care, and facilitates access to and coordinates with a broad range of specialty, ancillary, and community services.

- **Transitions**: A goal of the medical home is to optimize life-long health and well-being and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as an individual moves along and within systems of services and from adolescence to adulthood.

- **Value**: Owing to the importance of high-quality health care, appropriate payment for medical home activities is imperative. A high-performance health care system requires appropriate financing to support and sustain medical homes that promote system-wide quality care with optimal health outcomes, family satisfaction, and cost efficiency.

The family-centered medical home may be more important now than ever before. As concerns about the rising cost of health care mount, the medical home is recognized as an approach to delivering and organizing primary care that improves the experience of care, improves the health of populations, and reduces the per capita costs of health care. The federal government recognizes that the total health care costs for people with chronic disease account for more than 70% of the nation's health care expenditures. By providing the best patient- and family-centered care at every visit, the medical home efficiently uses limited resources and ensures that adequate payment is available to support practice activities.
Although the medical home concept may be new to some, its roots run deep. The term “medical home” was first used in a 1967 book, Standards of Child Health Care, written and published by the Academy. Throughout the 1980s and 1990s, the AAP clarified and broadened the definition of “medical home” from the concept of centralized medical records for children with special health care needs to a community-level focus on addressing the needs of the whole child and family in relationship to health, education, family support, and the social environment.

Over the years, the AAP has remained at the forefront, promoting the adoption and expansion of the patient- and family-centered medical home through numerous activities, such as educational initiatives, policy advancement, and national partnerships with the MCHB and other key stakeholders, as well as the provision of technical expertise. Among the Academy’s most important contributions has been its involvement in the NCMHI.

Created in 2008 via a cooperative agreement between the MCHB and the AAP, the NCMHI is housed within the Academy’s Division of Children with Special Needs in the Department of Child Health and Wellness. The mission of the NCMHI is to work in cooperation with federal agencies and other partners and stakeholders to ensure that all children and youth, particularly those with special health care needs, have access to a medical home.

In support of its goal to ensure the provision of health care services that are accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective, the NCMHI has developed and led numerous programs and initiatives that have increased awareness and understanding of medical home, as well as enhanced its practical application to improve child health care delivery and system design at the practice, community, state, and national levels.

“...the NCMHI, particularly in the last 3–4 years, has just taken off. It’s like a real lightning bolt of a resource now. It’s brought together so much important thinking and practical tools for implementation and opportunities for people to do thinking such as the ‘transition’ work...These have been really, really valuable resources that have come into the world that have helped to translate some of these good ideas into actual action on the ground...Fan Tait and Michelle Esquivel and the staff that they’ve put together that have made a huge difference in the NCMHI. They’ve been so instrumental in getting things moving.”

—Nora Wells, MEd, Director of Programs/Co-director, National Center for Family/Professional Partnerships

“...the evolution of their sophistication around both understanding medical home and understanding how to promote its implementation has made the NCMHI progressively more effective over the years so it’s changed from being a clearinghouse for anything out there that has medical home written all over it to really active, action-oriented, quality-improvement-oriented undertakings.”

—Carl Cooley, MD, FAAP, Medical Director, Crotched Mountain Foundation, Medical Director, Center for Medical Home Improvement, Co-chairperson, NCMHI Medical Home Implementation Project Advisory Committee
ABOUT THIS REPORT

This report provides a retrospective look at the NCMHI from 2008 to 2013, highlighting some of the National Center’s most important and impactful activities and accomplishments. The report is organized into sections around the National Center’s primary goals, which include:

- Building National Partnerships
- Creating the Tools
- Fostering Community and State Collaborations
- Integrating Medical Home Throughout the AAP

Each section describes initiatives, programs, and accomplishments that illustrate the National Center’s broad-based outreach and efforts to spread the concept of medical home not only within the AAP community of pediatricians but at the local, state, and national levels. Throughout the report, readers will also get the perspectives and experiences of some of the many partners, stakeholders, and thought leaders who have been so much a part of building family-centered medical home and the NCMHI.

“I see the National Center as a core source for information about how to develop and implement medical home....”
Karen VanLandeghem, MPH, Senior Advisor, Association of Maternal and Child Health Programs

For additional information about this report, contact the NCMHI staff at medical_home@aap.org or 800-433-9016, extension 7605. For additional information about the NCMHI, visit the NCMHI Web site at http://www.medicalhomeinfo.org/ or contact the National Center at medical_home@aap.org or 800-433-9016, extension 7605.
BUILDING NATIONAL PARTNERSHIPS

Just as building a child’s medical home over time requires a partnership between the physician and the family, so too diffusion and implementation of the family-centered medical home concept require partnerships. Because the family-centered medical home is a multifaceted model of care involving many different elements, its successful application requires a systems-based approach. Recognizing that neither individual health professionals nor even the AAP alone can leverage the kind of change needed, the NCMHI uses its resources, commitment, and multidisciplinary Project Advisory Committee to reach out to key stakeholders and support collaboration at the national level to foster policy- and systems-level change. In fact, the committee includes members from organizations representing families, nursing, primary care, and specialty care and has resulted in rich, interactive learning that members carry forward into their respective professional networks.

INITIATIVES, PROGRAMS AND ACCOMPLISHMENTS

Expanding Partnerships

The NCMHI extends the reach of medical home beyond the pediatric community by promoting partnerships with organizations such as the Patient-Centered Primary Care Collaborative (PCPCC) and primary care societies such as the American College of Physicians, American Academy of Family Physicians, and American Osteopathic Association (AOA). Just as critical are the partnerships developed between NCMHI and the National Association of Pediatric Nurse Practitioners and key family organizations such as Family Voices, National Partnership for Women and Families, and the Institute for Patient-and Family-Centered Care.

NCMHI staff participation in PCPCC activities ensures that children and pediatrics are included in PCPCC initiatives. For example, the National Center’s involvement with the PCPCC led to the inclusion of pediatric profiles in a PCPCC publication titled “Core Value, Community Connections: Care Coordination in the Medical Home,” which focuses on promising practices in care coordination.

Building Relationships With Accrediting Organizations

The works with the National Committee on Quality Assurance (NCQA), the Utilization Review Accreditation Commission, The Joint Commission, and the Accreditation Association for Ambulatory Health Care to promote recognition of pediatric issues across each organization’s medical home programs.

The NCMHI has been integral in mobilizing AAP membership and other key stakeholders to gather and deliver comprehensive feedback influencing the development of the NCQA Patient-Centered Medical Home (PCMH) recognition program standards in 2008 and 2011. Because many states and communities are prescribing NCQA PCMH for their primary care practices, the NCMHI assisted in the development and publication of an online compendium of frequently asked questions to help explain how the NCQA PCMH standards specifically relate to pediatric care delivery.

NCMHI participation in the NCQA Physician Practice Connections®–Patient-Centered Medical Home Feedback Workgroup keeps the unique needs of pediatric clinicians and children and their families at the forefront.

“...the NCMHI is a very close partner of Family Voices and the National Center for Family/Professional Partnerships and it's the kind of organization and project that we feel we can go to and brainstorm about what are the best ideas for moving the whole agenda for family centered care forward and how can we work together to effectively spread best practices...the National Center is a thought leader...it brings together lots of different viewpoints.”

–Nora Wells, MEd, Director of Programs/Co-director, National Center for Family/Professional Partnerships
Collaborating with MCHB-Funded National Centers

All MCHB national centers share a commitment to improving the health and well-being of families and children—especially those with special health care needs—across the centers’ respective areas of focus. In an effort to share expertise and promote diffusion of innovations in child health, the NCMHI establishes partnerships and engages in collaborative projects with other MCHB-funded national centers, including the following:

- National Center for Family/Professional Partnerships
- National Center for Children’s Vision & Eye Health
- Catalyst Center
- National Center for Ease of Use of Community-Based Services
- National Health Care Transition Center
- Child and Adolescent Health Measurement Initiative

These collaborations have led to the development and dissemination of new resources and tools. One such collaboration involved the NCMHI and the National Center for Cultural Competence, which worked together to identify promising practices regarding access to and delivery of language services in the medical home for patients and families with limited English proficiency. By sharing their findings at national conferences such as the AAP National Conference & Exhibition and the Association of Maternal and Child Health Programs annual conference, the NCMHI helped to reach an even larger audience. Another collaboration, with the National Center for Children's Vision & Eye Health, resulted in the development of educational fact sheets for providers and families on the importance of vision screening in the medical home.

Outreach to Other Key Stakeholders

Health disparities associated with underserved populations make the provision of care within a medical home even more critical. Seeking ways to enhance pediatric medical home advancement for vulnerable children and their families, the NCMHI reaches out to the National Hispanic Medical Association and the National Alliance for Hispanic Health to share information and resources and learn more about activities and possible areas for partnership, cross-promotion, and advancement of the medical home model for underserved and vulnerable populations.

Empowering Families

The patient and the family represent the heart of the medical home, and ultimately it is their needs and voices that drive every aspect of the NCMHI. The NCMHI strives to integrate families within medical home implementation initiatives and partnerships at all levels. Through the efforts of the NCMHI, family members serve as faculty on webinars and at national meetings. The National Center’s Project Advisory Committee has included parents of children with special health care needs and organizations representing families and consumers as expert members, embracing their perspectives and contributions.

“...the National Center brings a broad and needed approach to implementation of medical home...we’re reaching pediatricians but also reaching other team members in a collaborative and supportive way...”

–Fan Tait, MD, FAAP, Associate Executive Director, AAP
Building a home—be it brick and mortar or medical—requires special tools, resources, and expertise. As the name NCMHI implies, implementation is at the core of NCMHI activities, and a significant component of NCMHI work involves developing, distributing, and evaluating resources that take family-centered medical home from principles to practice. Ever evolving to meet the needs of the diverse community it serves, the NCHMI listens closely to families, physicians, medical practices, public health practitioners, and others involved in medical home at the community, state, and national levels. Among its collection of tools and resources to promote and foster family-centered medical home understanding and implementation, the NCHMI provides a comprehensive Web site, an online toolkit, educational opportunities, social media outreach, and individualized expert technical assistance.

INITIATIVES, PROGRAMS AND ACCOMPLISHMENTS

The NCMHI Web Site

The National Center’s Web site (www.medicalhomeinfo.org) is a clearinghouse for practical tools, guidance, and information in support of the mission of ensuring that every child and youth has a medical home. Offering comprehensive implementation resources for pediatric clinicians, parents, caregivers, policymakers, and other key stakeholders, the Web site advances the medical home approach to care and provides information about how practices, families, communities, and states are working toward implementation.

A number of NCMHI resources available via the Web site and targeted for use by families were recently translated into Spanish, including the “For Families—Community and State Resources” Web page; medical home fact sheets for parents, children, and youths; and other popular tools such as the Pre-visit Contact Form and Family Exit Survey.

As the NCMHI has gained recognition as a premier source for medical home information and resources, its Web-based resources have drawn increasing attention each year. With over 2 million visits from 2009–2013, the Web site continues to evolve to meet the needs of its users. User feedback fueled a redesign of the site in 2010, and the NCMHI continues its efforts to enhance content and usability by regularly engaging in quality improvement through visitor evaluations and user testing. Furthermore, NCMHI developed a brief video tutorial to introduce new users to the navigation of the online toolkit. In a 2011 survey, more than three out of four users found the Web site “useful,” “current,” “easy to read,” and “easy to comprehend.”
“Building Your Medical Home” Toolkit

Taking family-centered medical home from concept to practice is the goal of the NCMHI "Building Your Medical Home" toolkit (http://www.pediatricmed-home.org/). The toolkit supports development and improvement of a family-centered medical home. In addition to providing a basic primer on the medical home model, this free online resource can help a practice apply for recognition as a national patient-centered medical home. Toolkit users include not only AAP members but other health care professionals as well as parents and caregivers. The toolkit has been widely promoted within the Academy as well as by national partners including the PCPCC, MCHB national centers, and the Alliance for Information on Maternal and Child Health. Use of the “Building Your Medical Home” toolkit continues to grow. To help visitors navigate the toolkit, the NCMHI developed a video tutorial that guides users through six key building blocks. The tutorial is located on the toolkit’s home page (www.pediatricmedhome.org)

Registered Users of the Building Your Medical Home Toolkit

Educational Offerings

From the inception of the NCMHI, one of its important functions has been to offer practice-focused educational resources and training around medical home and quality improvement. In 2009, the NCMHI collaborated with the AAP Division of Community-Based Initiatives to lead a Continuing Medical Education–bearing, five-part webinar series focused on topics such as co-management between primary and specialty care, developmental screening, early intervention, and family-centered care. Led by recognized experts, these sessions highlighted key strategies for implementation at the practice level and attracted more than 1,200 participants from across the country including pediatricians, family physicians, nurses, family advocates, and public health administrators.

In 2011, the NCMHI delivered a second webinars series, attracting a national audience of 914 participants with diverse backgrounds in child health, including primary care providers, specialty providers, medical students, family advocates, and public health administrators. Across four webinars, presenters carefully examined the role of the patient/family/provider partnership in the effective delivery of preventive, acute, chronic, and complex care.

“It was very exciting for me as an interpreter to see that there are physicians that are aware of the needs of patients with LEP as well as the importance of having certified interpreters”.
Participant of the ‘How to Enhance Care Delivery for a Diverse Patient Population’ webinar on March 27, 2013

“Some webinars are opportunities to multi-task....this one I listened to the entire hour. It was really quality material that provided a strong picture of evidence-based practice - FCC is so hard to quality and quantify... I intend to download and listen to it again and forward the link to others in my office.”
Participant of the ‘How to Incorporate Best Practices in Family-Centered Care in Your Practice’ webinar on May 29, 2013
Building on the success of the previous offerings, the NCMHI offered a third set of webinars in 2013 as part of the Medical Home in Pediatrics: The HOW TO Webinar Series, featuring topics such as youth empowerment in the medical home setting, family-centered care, language-access services, and data use in practice. The popularity of this NCMHI webinar series is evidenced by the registration numbers—some NCMHI webinars have reached capacity within 1 hour of registration opening. In total, the four webinars attracted more than 900 participants. Beyond enrollment, the value of these webinars is measured in what participants take away.

**Technical Assistance**

NCMHI staff has an extensive knowledge base around all facets of the family-centered medical home, and that expertise is used to provide individualized technical assistance through online, telephone, and in-person consultation with providers, families, AAP chapters, state and community agencies, and many other diverse audiences. Between 2008 and 2012, NCMHI staff fielded over 2,750 requests from physicians, parents, child advocates, health care professionals, and others. The number of requests received has increased each year, as have the sophistication and complexity of the queries.

- **Technical Assistance requests have come from all 50 states, the District of Columbia, Guam, and Puerto Rico**
- **The type of assistance sought varies widely, ranging from questions regarding education, case coordination, and quality improvement to requests for condition-specific information within the medical home context.**
- **Technical Assistance example: A team of residents in child and adolescent psychiatry reached out to the NCMHI for help in developing content for a lecture series to teach other residents, including pediatric residents, about how and why to collaborate as clinicians via the medical home model. NCMHI provided them with targeted resources on the NCMHI Web site (resources on co-management, the role of subspecialists in the medical home model), as well as from the AAP (implementation and educational tools on delivering mental health care in primary care). NCMHI staff also scanned internal and external outlets to find several promising practices on this topic for the residents to consider across a range of settings in their community (hospital, health department, urban clinics).**

"I really enjoyed the webinar. I have been a nurse for 25 years and advanced practice for about 15 of those. It is still refreshing and educational for me to hear the patient's story, especially those patients who are articulate about the finer points of their care. We are working very hard to move the culture on transition at our clinic so these webinars help to keep us focused and on track."

Participant of the ‘How to Engage Youth in their Health Care’ webinar on February 27, 2013

"Fantastic service that got me exactly what I needed very quickly. Far exceeded expectations and much appreciated."

Technical Assistance inquiry regarding access to care plan templates for patients at a pediatric primary care practice.

• 2,900 individuals participated in the 2009, 2011, and 2013 series webinars
• 85% of participants said that the webinars provided practical, usable information
• 75% of participants learned something through the webinars that they planned to implement in practice
National Child Health Day 2009

The first Monday in October is National Child Health Day. In 2009, the theme “Every Child Deserves a Medical Home” provided the NCCHI an opportunity to highlight the importance of medical home to a broad audience. From creating a video (http://www.medicalhomeinfo.org/about/medical_home/media.aspx) featuring children, families, and health care providers speaking to the value of medical home, to hosting a webinar offering provider and parent perspectives on the history, meaning, and significance of medical home, to informational handouts for families and coloring books and bookmarks for children, the NCCHI capitalized on the occasion to educate and celebrate.

EQIPP Medical Home for Pediatric Primary Care Module

Education in Quality Improvement for Pediatric Practice (EQIPP) is the unique online learning program of the AAP that weaves improvement principles and concepts with pediatric-specific clinical content. The NCCHI contributed its resources to the development of an EQIPP module on medical home, which is approved for Part IV Maintenance of Certification credit for AAP membership. The module focuses on essential components of family-centered medical home, such as team-based care, patient population management, care coordination, family centeredness, and access to care. Basic quality improvement education, techniques, and support to pediatric practices are also included.

“...the resources...the Medical Home Toolkit...the Medical Home EQIPP [Education in Quality Improvement for Pediatric Practice] module...are things I refer people to all the time when they’re asking ‘where can I find some resources that will help me become more of a medical home?’”

Carl Cooley, MD, FAAP, Medical Director, Crotched Mountain Foundation and Rehabilitation Center, Medical Director, Center for Medical Home Improvement, Co-chairperson, NCCHI Medical Home Implementation Project Advisory Committee
Social and Electronic Media Outreach
Recognizing changes in the way information is sought and obtained, the NCMHI has prioritized the creation of a social media presence to promote awareness of its services and resources.

In 2010, the NCMHI launched a Facebook page (www.facebook.com/medicalhome) and has rapidly amassed over 795 followers. Additionally, in early 2012, a YouTube channel was created and currently hosts more than 70 short educational videos featuring medical home experts and parent partners discussing core components of medical home implementation. In its brief existence, the channel has already received over 12,350 video views.

To inform constituents of breaking news, the NCMHI also maintains a monthly online e-Newsletter, Medical Homes @ Work (www.medicalhomeinfo.org/about/newsletter), providing information about the latest medical home implementation advancements, resources, and training events. The quarterly version of the newsletter, Spotlight on Child Health Issues and Medical Home (www.medicalhomeinfo.org/about/newsletter/archive/#spotlight), features in-depth reviews of specific health topics such as cultural effectiveness, family-centered care, mental health, asthma, and health information technology within the context of the medical home. Both resources are distributed through an email list boasting a subscription base that has more than doubled in size, from 2,000 in 2008 to 4,400 in 2013.

Care Coordination Training Pilot Project
In cooperation with the MCHB, the NCMHI is facilitating the implementation of a standardized pediatric-specific care coordination curriculum, developed by the Boston Children's Hospital and funded by the MCHB. Designed to support care coordination activities in the pediatric family-centered medical home, the curriculum includes materials, resources, and information that can be made available to state programs or delivery-system entities engaged in medical home implementation. The curriculum provides an opportunity for formal instruction to individuals in pediatric practices who are responsible for care coordination activities. After a pilot test of the curriculum was completed in Florida, the NCMHI provided training in three additional states in 2013—Portland, OR; Denver, CO; and Anchorage, AK—in a new effort focused on formal teaching of the curriculum and assessing its effectiveness. Thus far, the training sessions have been well received, with participants specifically appreciative of the practical application of the curriculum. At the conclusion of this pilot, over 80 care coordinators will have participated in the training.

“Pediatric professionals are very aware of the importance of family centered medical care and the resources of the NCMHI...[I am] constantly using the resources in teaching, dissemination, presentations, writing of articles. The resources are outstanding...the incredible hard work and expertise of the project is coupled with the professional input and teamwork to produce outstanding products, to disseminate the work, to continue to evolve as the needs evolve...”

Linda Lindeke, PhD, RN, CNP, past president of the National Association of Pediatric Nurse Practitioners, Associate Professor, Director of Graduate Studies, School of Nursing, University of Minnesota

“...[the NCMHI]...and the leaders have cultivated a knowledgeable, passionate staff...they are among the strongest pediatric medical home experts around...and I would say that the NCMHI has made very good use of information and technology and communication through the Internet.”

Carl Cooley, MD, FAAP, Medical Director, Crotched Mountain Foundation and Rehabilitation Center, Medical Director, Center for Medical Home Improvement, Co-chairperson, NCMHI Medical Home Implementation Project Advisory Committee
In 2010 and 2013, the NCMHI published two monographs disseminating information about measurement and best practices on medical home implementation. The first, titled *Measuring Medical Home: Tools to Evaluate the Pediatric Patient- and Family-Centered Medical Home*, identifies tools for determining whether a patient-centered medical home achieves high-quality primary care. The monograph also provides an overview of 12 resources for evaluating practices on the continuum of transformation to a medical home. The second monograph, *Positioning the Family and Patient at the Center: A Guide to Family and Patient Partnership in the Medical Home*, includes research supporting the evidence base for family- and patient-centered care, a review of available tools to support partnerships with families and patients during practice transformation, and examples of best practices of such partnerships. Both monographs are available on the NCMHI Web site to download for free.
While recognizing that medical home advancement can be facilitated at the national level, the NCHMI also works to cultivate and sustain partnerships at the state and community levels as well. Through numerous activities, the NCMHI maintains an on the ground presence, connecting states with AAP chapters on issues germane to pediatric family-centered medical home, enhancing data access to support local decision making, advocating for inclusion of family voices in medical home discussion, and educating the next generation of physicians in family-centered medical home principles and implementation.

INITIATIVES, PROGRAMS AND ACCOMPLISHMENTS

Connecting Through Key Stakeholders in States

The NCMHI has worked to forge links at many levels, including those involving state and local partners. The NCMHI team coordinates quarterly conference calls and direct mail outreach to staff and leaders from the Association of Maternal and Child Health Programs. This national-level partnership aims to bring together Family Voices, Title V, and AAP chapters at the state level to model the benefit of provider, state, and family collaboration.

The NCMHI also helped plan and participated in a meeting coordinated by the National Academy for State Health Policy and the Association of Maternal and Child Health Programs. The meeting brought state teams together to share information about state medical home programs and initiatives involving Title V, the Children’s Health Insurance Program, and Medicaid. Model programs are described in Making Connections: Medicaid, CHIP, and Title V Working Together on State Medical Home Initiatives, a white paper that resulted from the meeting and is available free online (http://www.nashp.org/sites/default/files/Medicaid_Collaboration-FINAL.pdf).

Medical Home Data Portal

Providing local and state leaders and decision makers with data-driven strategies to promote the value of the medical home model is the goal of the Medical Home Data Portal (http://www.childhealthdata.org/browse/medical-home). Launched in collaboration with the Child and Adolescent Health Measurement Initiative, the portal allows users to access data from the National Survey of Children with Special Health Care Needs and the National Survey of Children’s Health in a user-friendly, interactive way. State-specific Web pages and across-state comparisons provide quick access to important information on how children and youth experience care within a medical home. Since its inception in 2009, the portal has received more than 16,000 unique visits.

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<th>Medical Home State Data Pages</th>
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<td>Data Resource Center data query results pages</td>
<td>The medical home data from the two national surveys are among the top three results pages for most visitors. Excluding comparisons and state-level data, there were nearly 8,000 unique visits to medical home results pages.</td>
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Leadership Education in Neurodevelopmental Disability Partnership

The Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program, which is operated across the country within university systems, addresses national issues of importance to children with special health care needs and their families. Working with LEND, the NCMHI developed interdisciplinary medical home competencies, piloted through more than 10 LEND training programs throughout the country. As a result of this initiative, medical home is now included in the LEND grant guidance, helping to ensure that LEND program trainees understand, appreciate, and have experience with the medical home model of practice.

Resident Education Initiative Work Group

Comprising residency program directors and medical home experts, the National Center's Resident Education Initiative Work Group addressed needs in resident education related to core tenets of the medical home with an emphasis on training related to care coordination, family-centered care, and children and youth with special health care needs. The efforts of the work group resulted in the development of a medical home curriculum for residency training programs. The AAP is partnering with the Academic Pediatric Association Continuity Research Network to pilot test and evaluate the curriculum through the network's member of continuity clinics.
INTEGRATING MEDICAL HOME THROUGHOUT THE AAP

Ultimately, the pediatric family-centered medical home is built upon a foundation of relationships between the pediatrician, child, and family. Pediatricians are at the forefront of the family-centered medical home. By educating and inspiring the Academy’s national and state leaders to promote medical home in their respective roles, as well as by infusing, the NCMHI plays a pivotal role in instilling the principles of family-centered medical home throughout the AAP.

INITIATIVES, PROGRAMS AND ACCOMPLISHMENTS

Medical Home Webinars for AAP Leaders

To inform AAP leadership of current efforts related to medical home both at the Academy and nationally, NCMHI staff organized a series of calls/webinars for AAP leaders to enhance their awareness of medical home initiatives at the national, state, and practice levels. The webinars also served as an open forum for discussion. More than 170 AAP leaders took part—learning about the history of medical home, medical home as an AAP priority, the intersection of medical home and health care reform, efforts related to supporting the health care transition from adolescence to adulthood, and activities related to medical home and health information technology. The Academy’s chapter leadership was encouraged to share what they learned with their respective members as a way to further disseminate information and resources.

Medical Home Chapter Champions Program

Working collaboratively within the AAP, the NCMHI identified at least one individual to serve his or her AAP chapter as a Medical Home Chapter Champion. These individuals are responsible for leading the efforts of health care providers regarding medical home in their states. To date, 55 pediatricians (representing more than 90% of all US AAP chapters) serve as Chapter Champions and represent a diverse group of primary and subspecialty pediatricians. The NCMHI fosters connections between Chapter Champions and others in their respective states who work on medical home initiatives; the NCMHI also provides technical assistance and support to Chapter Champions—as key stakeholders in medical home implementation—when necessary.

Strategy Forum—Addressing Specialists and Medical Home

One challenge in the family-centered medical home is defining the role of—and interface between—various types of pediatric clinicians, from general pediatricians to pediatric subspecialty providers. To promote understanding and encourage dialogue, the Academy convened a forum focused on these issues, and the NCMHI played a key role in implementing the forum. The long-term goal is to generate guidelines based on the principles established by these key stakeholders and disseminate them into existing AAP medical home priorities and larger organizational objectives and activities. A discussion paper including recommendations for the Academy, pediatricians, and a broader pediatric audience has been written and will be disseminated broadly. These recommendations will form the basis for a future practice-based quality improvement project and other activities.
**AAP Staff Workgroups**

Fostering collaboration on medical home activities within the Academy has been a hallmark of the NCMHI. NCMHI staff members participate in monthly cross-departmental meetings to share information and updates about priority projects, activities, and initiatives related to medical home; NCMHI staff members also play an integral role in several AAP interdepartmental groups including those focused on quality improvement, policy development, and social media.

Because the NCMHI maintains high visibility throughout the Academy, numerous collaborative projects and associated resources have been developed to advance the medical home model, such as the publication of fact sheets for providers and families describing the use of health information technology.

**AAP Periodic Survey of Fellows**

How does the NCMHI know whether its activities are making a difference within the pediatric community? A 2012 periodic survey commissioned by the NCMHI and conducted by the AAP Department of Research addressed this question by examining pediatricians’ opinions of and approaches to pediatric family-centered medical home. The survey findings suggest that NCMHI efforts to impart the value and importance of family-centered medical home to Academy membership is working.

Approximately three-fourths of survey respondents agreed that having a family-centered medical home:

- improves children’s health care
- encourages patient use of preventive care
- decreases unnecessary or preventable emergency department use and hospitalizations
- reduces health care costs by avoiding duplication or unnecessary testing and services

Over 90% of the respondents indicated that they support a family-centered care partnership by offering services such as same-day scheduling, telephone access, urgent phone advice callbacks, and language-specific education materials. More than two-thirds also regularly offer extended hours, a range of payment options, health insurance information resources, and interpreter services. In addition, 80% of pediatricians reported that the patients and families for whom they care are “actively involved” in health care decision making.

“…thanks to the efforts of the NCMHI and the [Medical Home Implementation] Project Advisory Committee, it was able to achieve recognition by the AAP that the medical home was a fundamental concept that it endorsed and supported… I think they have made their primary care members understand that this is a model of care worth aspiring to.”

Carl Cooley, MD, FAAP, Medical Director, Crotched Mountain Foundation and Rehabilitation Center, Medical Director, Center for Medical Home Improvement, Co-chairperson, NCMHI Medical Home Implementation Project Advisory Committee
The gold standard of health care is for every individual to get care that is accessible, continuous, comprehensive, patient- and family-centered, coordinated, compassionate, and culturally effective. These characteristics define the family-centered medical home model—a model that has become a reality for an increasing number of children and their families, thanks in part to the work of the NCMHI.

Over the past 5 years, as described in this document, the NCMHI has spearheaded broad-based implementation initiatives that have heightened public awareness and understanding of medical home, as well as equipped pediatric clinicians across the country with essential training and tools for developing and enhancing the medical home model in practice. By forging relationships with key stakeholders from community organizations to national accrediting organizations, as well as by expanding the reach of the medical home model at the AAP and via various government agencies and nonprofit organizations, the NCMHI has ensured that the needs of children and families are not forgotten.

Along with these achievements, additional work remains to be done in advancing the medical home model for all children and youth. Medical home transformation requires continuous development, ongoing quality improvement, family partnership skills, teamwork, and strong care coordination functions. The NCMHI anticipates several areas of special interest that will impact the success of the medical home and the well-being of children across the country: access to family-centered care for vulnerable populations, care coordination between primary care and specialty care providers, team-based care, and provider payment for quality of care.

Access to Family-Centered Care for Vulnerable Populations
The MCHB characterizes family-centered care as that which assures the health and well-being of children and their families through a respectful family-professional partnership. This partnership honors the strengths, cultures, traditions, and expertise that all parties bring to the relationship. “The term vulnerable population refers to social groups with increased relative risk (i.e. exposure to risk factors) or susceptibility to health-related problems. This vulnerability is evidenced in higher comparative mortality rates, lower life expectancy, reduced access to care, and diminished quality of life.”

Ongoing efforts are still needed to accomplish the universal adoption of the patient- and family-centered medical home model of care. Clinicians and teams require continued support in identifying patient and family needs, connecting their patients and families to community-based resources, and communicating effectively with community-based service providers. Access to care, coordinated care delivery through the medical home model, and quality improvement will help provide equal opportunities for everyone to lead healthy lives.”

“What is it that we can do better? What is so critically important is having families be part of quality improvement initiatives within a practice...how are you going to get better unless the families are involved in that?... The family has to always be at the center...”
Fan Tait, MD, FAAP, Associate Executive Director, AAP
Care Coordination Between Primary Care and Specialty Care Providers

Children are increasingly using specialty medical services; in 2009, more than 13 million pediatric visits resulted in referral to another physician.\textsuperscript{ii} The growing recognition of the medical home as the optimal approach to pediatric primary care for all children highlights the need for care integration across primary and subspecialty care settings.\textsuperscript{iii} Despite the recognition that integrated care can improve outcomes, fewer than half of pediatric primary care clinicians report that patient care plans are integrated with subspecialists.\textsuperscript{iv}

According to the 2009/2010 National Survey of Children with Special Health Care Needs, approximately 11.2 million children ages 0–17 years in the United States have special health care needs, and the majority of these children have complex service needs that go beyond a primary need for prescription medications to manage a health condition. Access to pediatric subspecialty care is a significant element of an effective medical home for children with special health care needs; however, there are some challenges associated with that access, including an insufficient number of pediatric subspecialists, dramatically increasing demand for pediatric care, and a fragmented and inefficient system of pediatric primary and specialty pediatric care.

Team-Based Care

Medical home implementation results from teamwork within a practice setting. Teamwork involves a set of cross-disciplinary interaction skills that must be learned, practiced, and refined to better manage care delivery, promote safety, and enhance outcomes. Highly functioning teams are made up of those on the front lines of care. They engage family partners, have the capacity to test changes quickly, and possess the resilience to deal with the complexities of primary care. If medical home is to advance, practices must continue to organize and utilize their entire staff efficiently to comprehensively serve their patients and families. Team-based care will become especially important for meeting the challenges of treating a more diverse patient population amid the shortage of pediatric primary care workers that is projected for future years.

Payment for Quality of Care

Appropriate payment for medical home activities has long been an issue. Demonstration projects across the country are exploring ways to implement better care coordination, meaningful use of health information technology, better communication between patients, and providers and a team approach to care. However, efforts to transform health care delivery depend on sustainable financing models, especially as more primary care providers shift employment from small practices to larger integrated systems of care and Accountable Care Organizations. Without changing the way health care is purchased, providers will have no incentive to move away from a system that promotes health care volume to a system that rewards health care value.\textsuperscript{v}

\textsuperscript{ii} According to the 2009/2010 National Survey of Children with Special Health Care Needs, approximately 11.2 million children ages 0–17 years in the United States have special health care needs, and the majority of these children have complex service needs that go beyond a primary need for prescription medications to manage a health condition. Access to pediatric subspecialty care is a significant element of an effective medical home for children with special health care needs; however, there are some challenges associated with that access, including an insufficient number of pediatric subspecialists, dramatically increasing demand for pediatric care, and a fragmented and inefficient system of pediatric primary and specialty pediatric care.

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A Retrospective Look at Programs and Initiatives Toward
A Family-Centered Medical Home for Every Child and Youth


