

The Family-Centered Medical Home: Specific Considerations for Child Health Research and Policy

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Since the initial conceptualization of the medical home in the 1960s and 70s in pediatrics,¹ its definition and principles have evolved. The addition of clinicians in family medicine and internal medicine, policymakers, payer groups, and consumer groups to medical home study and implementation has given tremendous positive momentum to the movement to create patient- and family-centered medical homes for children, adolescents and adults. While there is a great deal of similarity between medical home concepts and models for the care of adults and children, some principles should be emphasized in child and adolescent health, and a few health concepts are unique. These have important implications for how child-relevant research and policy related to the medical home should be promoted. This paper describes perspectives on the primary care medical home from the standpoint of child and adolescent health.

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THE NEED TO ARTICULATE THE FAMILY-CENTERED MEDICAL HOME FOR PEDIATRICS

The *medical home* model of care has been defined by several organizations during the past 2 decades. The American Academy of Pediatrics defined the medical home in its policy statements of 1992 and 2002 as care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective; delivered or directed by well-trained physicians who provide primary care and manage and facilitate essentially all aspects of pediatric care, with a physician known to the child and family and able to develop a partnership of mutual responsibility and trust.² Extending this to the provision of health care for all Americans, a joint effort by the American Academy of Pediatrics, the American College of Physicians, the American Osteopathic Association, and the American Academy of Family Physicians published a set of joint principles for the *patient-centered medical home* (PCMH), integrating patients as active participants in their own health and well-being, cared for by a physician leading the medical team that coordinates all aspects of preventive, acute, and chronic needs of patients by using the best available evidence and appropriate technology.³ Some controversy has been generated by the use of the word *physician* as team leader in both of these statements, and others have suggested the use of the term *health home* in place of *medical home*, to emphasize the inclusion of oral and mental health into the model; whichever phrase is chosen, however, the main idea is that of a well-coordinated team, with a clinician as the leader.

The medical home is being embraced as official policy by an increasing number of organizations in both the health care and business sectors. While there is a great deal of similarity between these definitions, they place somewhat different emphasis on the role of the family and community

in practice, with the “consumer” often the patient in adult health care (hence, PCMH) and parents and child together in child health care (family-centered medical home [FCMH]).

The medical home in child and adolescent health settings has several key elements. Care is delivered using a population-based approach: registries of children and adolescents with chronic conditions are created with information about condition severity, diagnoses, and needed supports; care is coordinated with the multiple health and related services that children and families need; parents (and children/youth when appropriate) are involved in decision making and practice-based quality improvement; clinical practice standards reflecting children’s conditions are applied; newborn screening and surveillance ensues for developmental milestones and unique conditions; and children/youth and families are educated about their conditions. Typically, medical home arrangements include teamwork in practices, with nurses and other nonphysician personnel taking active roles.⁴ For children and adolescents, coordination of care involves a number of community agencies, especially schools, for which equivalents in the care of adults with chronic conditions are limited.

The value of the medical home model of care is being demonstrated by an increasing number of studies in both the child and adult literature, at both the microsystem level (ie, one or a small group of practices) and the macrosystem level (ie, an integrated delivery system such as Geisinger Health System).⁴ Outcomes that have been investigated include cost savings, appropriate utilization of services, avoidance of emergency department and inpatient hospitalizations, and quality of life from the perspectives of patients (lost school days) and families (decreased stress, lost parental work time).^{5–7} A recent literature review by Homer and colleagues⁸ summarized the current literature in child health: while the preponderance of evidence indicated a benefit, few studies examined the value of different medical home components in isolation. Several measures of “medical homeness” have been developed for use in both the child and adult settings, which begin to address this issue, but they are diverse in scope, and some are more useful as quality improvement tools than as research instruments. Work to operationalize and measure the various elements of the medical home for research purposes is essential, to enable data collection about which components are likely to improve outcomes in which settings. This work is important to inform changes in policy and practice. Fortunately, recent legislation reauthorizing the Children’s Health Insurance Program (CHIP) may enable development of such measures as part of a broader effort to develop measures of child health care quality, and the prominence of the medical home concept within health care reform legislation may help articulate this value further.

The focus of PCMH-relevant research in adult health care has been mainly aimed at demonstrating the value of changes in primary care health services delivery for single, high-prevalence conditions such as type 2 diabetes.⁹ Many studies have examined the use of information technology solutions

at the practice level to promote guideline-concordant care.^{10–12} Outcomes have focused primarily on short-term, highly measurable disease-specific outcomes, as well as appropriate utilization and cost savings. Many of these studies are of high quality, as measurement of predictor and outcome variables is highly reliable. However, their use in helping inform policy for the FCMH in child health is limited.

The global value of the medical home has been adequately addressed by the American Academy of Pediatrics and other organizations. This statement focuses more specifically on policy-relevant research directions that might best inform policy on the delivery of child and adolescent health care. The Academic Pediatric Association (APA) is uniquely positioned to address this issue, as it sits at the intersection of research, policy, and education related to general pediatrics.

ISSUES UNIQUE TO CHILDREN AND ADOLESCENTS: THE 5 D’S

Forrest and colleagues¹³ conceptualized unique issues for children compared to adults in health services research as the 4 D’s: developmental change, dependency, differential epidemiology, and demography. Financing of child health services (the fifth D: dollars), while more of an external characteristic, is different as well. These differences influence how the FCMH is operationalized for child versus adult health care systems (Table).

Development

While adult health care often focuses on health maintenance and prevention of poor sequelae associated with inadequate care or disease progression, child health care is conceptualized as a resource that enhances children’s upward developmental trajectory. For children with chronic conditions, the prevalence and severity of many conditions change with age, so the burden of illness in the same population within a practice is dynamic. Consequently, the composition of a child’s care team can shift rapidly, and care plans may need more frequent modifications than for adults. Second, the focus of developmental services and related therapies is habilitative, not rehabilitative, making the distinction between short-term and long-term rehabilitation often used in adults of little value when applied to children. Third, as children develop, their cognitive skills to enable understanding and use of clinical information, symptom recognition, decision-making skills, and self-management skills all typically increase. Finally, children become adults, and their primary care, specialty care, and community supports all transition from the child to the adult sector.

These characteristics generate the following needs:

- care coordination needs change as children and adolescents grow and develop;
- developmental services must focus on maximizing potential and independence rather than regaining lost skills;
- evaluation of the FCMH for children must include functional and developmental outcomes;¹⁴

Table. The 5 D's, Highlighting Unique Differences Between the Adult Versus Child/Adolescent Medical Home

The 5 D's	Adults	Children/Adolescents
Developmental Change	<ul style="list-style-type: none"> • Health maintenance • Prevention of adverse sequelae 	<ul style="list-style-type: none"> • Enhance developmental progress
	<ul style="list-style-type: none"> • Rehabilitative 	<ul style="list-style-type: none"> • Habilitative
Dependency	<ul style="list-style-type: none"> • Independent and autonomous 	<ul style="list-style-type: none"> • Dependent on adults • Parents are essential partners • Team members: family, child care providers, teachers, others
	<ul style="list-style-type: none"> • Patient-centered Medical Home 	<ul style="list-style-type: none"> • Family-centered Medical Home
Differential Epidemiology	<ul style="list-style-type: none"> • Large number of common chronic conditions (ie, heart disease, diabetes, hypertension) 	<ul style="list-style-type: none"> • Predominantly healthy • Large number of relatively rare chronic conditions
	<ul style="list-style-type: none"> • Subspecialists in the community 	<ul style="list-style-type: none"> • Subspecialists based in academic medical centers
Demographic Patterns	<ul style="list-style-type: none"> • Poverty among elderly has declined in part due to Medicare 	<ul style="list-style-type: none"> • Disproportionate rates of poverty • Disproportionate racial and ethnic diversity
Dollars	<ul style="list-style-type: none"> • Higher health care costs 	<ul style="list-style-type: none"> • Overall costs small
	<ul style="list-style-type: none"> • Private insurers and Medicare 	<ul style="list-style-type: none"> • Private insurers, state Medicaid, CHIP*
	<ul style="list-style-type: none"> • Focus on return on investment on secondary and tertiary prevention 	<ul style="list-style-type: none"> • Return on investment over long term life course

*CHIP = Children's Health Insurance Program.

- special issues of adolescents and their transition to adulthood, including consent and confidentiality, must be addressed.

Dependency

Children depend on parents and other adults in their community, especially from educational and legal standpoints. This dependency, with only limited parallels in adult medicine, means that parents are critical partners in a child's care. Family well-being very much affects child

health and well-being. Thus, children's dependency calls for a broad clinical focus on the whole family. Other caregivers, including relatives, nonrelatives in a home or child care setting, and center-based child care providers, are also important partners. Similarly, the key role of schools for children and adolescents and their participation in the management of health conditions calls for a partnership with the educational sector that has no close parallel in adult medicine. Further, as adolescents mature, their role in this relationship changes and must be recognized. Practices and the broader health care system need to be

designed with dependency issues in mind and must nurture that relationship.

These characteristics generate the following needs:

- community collaboration and coordination must include early education and child care, schools, and families as key partners;
- services, supports, and evaluation must include the health and functioning of families, recognizing that most children have minimal autonomy in health care, but that this autonomy increases during the developmental process.

Differential Epidemiology

Children are primarily healthy, and the epidemiology of chronic conditions in children is somewhat different from that in adults. Related implications for practice design for the family-centered medical home include a greater emphasis on primary and secondary prevention strategies than in adults, and a different approach to caring for the population of children with chronic conditions. Beyond obesity, mental health disorders (ie, attention-deficit/hyperactivity disorder and depression), and asthma, there are fewer concentrations of children with specific conditions, (such as coronary artery disease, hypertension, and type 2 diabetes in adults). Instead, there are many relatively rare conditions spread among the population of children with chronic conditions.¹⁵ Consequently, “noncategorical” approaches to service provision, which are applicable across multiple conditions,^{16,17} are more suitable to the care of children. Care coordination, for instance, should address needs common to multiple conditions, such as coordination between the medical home and multiple specialty providers, community services, and schools. Because of the relative rarity of many conditions in children, most pediatric subspecialists are based in academic health centers, resulting in relatively more difficult access. While there are few primary care providers that are experienced in treating adults surviving the complex chronic conditions of childhood,¹⁸ many adult medical and surgical subspecialists work in community settings, creating easier access to subspecialty care for adults.

These characteristics generate the following needs:

- prevention is critical, especially for more common conditions such as obesity, asthma, and mental health conditions;
- programs should address chronic conditions in general using a noncategorical rather than a disease-specific approach;
- children need access to pediatric subspecialists who can coordinate activities with one another as well as with the medical home;
- frequent comanagement of conditions with subspecialists requires considerable clinician time and practice resources.

Demographic Patterns

Children and adolescents have disproportionately high rates of poverty, with nearly 13 million children (17%) in

poverty.¹⁹ While the prevalence of poverty among elderly populations has dropped dramatically in the past 40 years, partly in association with the introduction of Medicare, the prevalence of childhood poverty has changed little. The pediatric population is also more racially and ethnically diverse than the adult population.²⁰ Poverty and diversity make children particularly vulnerable to poor health status and poor quality of care. The FCMH must have a focus on eliminating health disparities and addressing social determinants of child health.

These characteristics generate the following needs:

- substantial investment is needed to understand and address social determinants of child and adolescent health;
- evidence-based interventions (eg, home visiting and Head Start) and coordination with these interventions must be supported, and these team members must be part of the FCMH team;
- addressing racial/ethnic and socioeconomic disparities must be a priority in child health, with implications for adult health.

FINANCING ISSUES (DOLLARS)

Payor Differences

Major differences exist in health care financing as compared with adults, especially those with low socioeconomic status. While the overall costs of health care for children are small compared with the adult population, they are a critical investment that may result in substantial savings over the life span.²¹ Services are provided by a diverse mix of private insurers and state Medicaid and Children’s Health Insurance Program funds, rather than Medicare, and funding for mental health and oral health care is typically “carved out” of insurance policies, further increasing complexity. Unlike Medicare, Medicaid and the Children’s Health Insurance Program have major variations from state to state and, on average, reimburse providers at 60% of the Medicare rates for the same service.²² However, the advent of health care reform will create parity between Medicaid and Medicare payments for 2 years, which will change the payment landscape. Implementation of this landmark legislation will need to be monitored to understand its impact on financing of FCMH for children and adolescents.

Without a comprehensive national approach to financing, health reform may perpetuate the current system of “50 different ways to pay for children’s health care,” with the potential to create a tremendously fragmented system for financing the FCMH for children and adolescents.

Return on Investment

Health care finance policy leaders reasonably expect that there will be a measurable return on investment (ROI) for outcomes from care delivery.²³ As techniques for managing chronic conditions in the FCMH model focus primarily on secondary and tertiary prevention, there is the potential of yielding measurable gains in ROI due to early modification of the disease course and prevention

of expensive complications and poor outcomes.²⁴ This is a highly visible aspect of current Medicare medical home demonstration pilots in adults. Evaluating the ROI for children can be challenging, as financial benefits may accrue over a much longer time frame than in adults, and savings are likely to occur less in the medical care system and more in long-term quality of life.²⁵ For example, Medicaid programs may be reluctant to reimburse for early intervention in obesity because the ROI in 2 to 5 years will not reflect the societal or personal health gains seen decades later.^{26–29}

Financing differences for children and adolescents indicate specific needs for the FCMH:

- need to evaluate the impact of health reform to promote a consistent base for financing child/adolescent health care
- financing proposals must consider child financing mechanisms and child benefits, using evidence about the impact of differences in these structures for children
- ROI evaluation must consider benefits outside the health care system
- a longer time horizon and scope are needed when measuring ROI
- child and adolescent health is an investment to prevent or delay future morbidity—a life course perspective is needed

SIMILARITIES BETWEEN PCMH AND FCMH

Care Coordination

Care coordination, an essential element of the pediatric and adult medical home, focuses on assuring that patients and families have access to needed care in a timely fashion, maximizing appropriate and efficient resource use while minimizing duplication of effort. In all age groups, there exist challenges with coordinating care between care settings, among community-based services, and with state and local service agencies.³⁰ To address these challenges, coordination of diverse services by using a comprehensive care plan, developed in partnership with patients, family members, primary care and specialty providers, and outside service providers, is similar and useful.³¹ This service is not explicitly provided by most primary care practices but is essential to maximize met needs for patients and families and to boost practice efficiency.

Continuity of Care Over Time and Transitions

Intrinsic to both pediatric and adult medicine are challenges with handoffs when a patient changes health care or service providers, moves between outpatient and inpatient settings, or into the community. Transitioning care to adult services for youth with special health care needs is further complicated by reductions in coverage for services as youth age out of public or private insurance, coupled with few adult-oriented providers with expertise in pediatric onset adult chronic conditions.³² Communication between pediatric and adult providers is rare.³³ Failure to ensure adequate transition from hospital to home, or from provider

to provider, fosters adverse patient outcomes and increased health care expenditures.

Centering Care Around the Family and Community

Families play critical roles for patients of all ages. Although many adult patients manage their own care, growing numbers of elderly patients require assistance from family members.³⁴ Patients and families as consumers have a central role in the care experience. The terminology of *patient-centered* versus *family-centered* medical home may differ slightly, but the idea is the same. Both environments call for consumer involvement and engagement. Similarly, extending the reach of the medical home beyond the physician-patient unit is important for both adults and children, given the role of family supports and family members in optimizing health outcomes.

In the PCMH and FCMH, coordination with the patient's work and community is critical. Whether consulting with employers and nursing homes or with schools and child care centers, the principles are the same: children need to learn in the least restrictive educational environment promoting learning to their full potential, and adults need to work in environments maximizing their function and productivity. Consultation between primary care medical homes and school nurses or employee health resources has similar characteristics. Interestingly, another similarity between the adult and child medical home is a weakness in our ability to measure coordination across these systems (such as coordination between inpatient and outpatient settings, primary care and specialty providers, and physician and nonphysician providers). Measures need to be developed to evaluate this critical aspect of the medical home.

Comprehensive Care: Acute Care and Health Maintenance

In a medical home, both children and adults require the full range of care from health promotion, resiliency building, and risk identification to all levels of preventive care. Importantly, effective prevention in the child health setting is critical to improved health in adulthood (eg, developmental screening in early childhood, and identifying and treating depression in adolescents). While screening techniques and targeted conditions may differ, the idea of primary and secondary prevention is common to both age groups.³⁵

Cultural Competence and Compassionate Care

Cultural competence and compassion are principles of the FCMH for individuals of all ages. Since the medical home is based on effective communication, active involvement, and shared decision making with consumers, effective strategies are required to assure mutual understanding among consumers and providers about culture and language as they affect health care, and to assure competence in these areas in the medical home. Compassion in care refers to concerns for the well-being of the

patient and family, demonstrated in verbal and nonverbal interactions, building trust, and promoting therapeutic alliances with the child, family, and health professional. Integrating patient and family perspectives in care also may lead to more active engagement in the process of care, shared management, and increased satisfaction, ultimately leading to better outcomes.³⁶

APA CURRENT POLICY AND ADVOCACY ACTIVITIES RELATED TO THE FCMH

In 2008, the APA Task Force on the Family-Centered Medical Home was convened to participate in the planning of a PCMH conference, a collaborative effort of APA, the Society of General Internal Medicine, and Society of Teachers of Family Medicine. The conference was held in July 2009 in Washington, DC, with over 150 researchers, policymakers, and funders in attendance. The conference goal was to develop a policy-relevant research agenda to advance the PCMH. Five papers were commissioned expanding on key issues and challenges facing the broader implementation of the PCMH, which were actively discussed at the conference and will be appearing as a supplement to the *Journal of General Internal Medicine*. The APA Task Force on the Family-Centered Medical Home has continued work with the Health Care Delivery Committee in developing this policy, tracking health reform efforts, presenting at the Pediatric Academic Societies' meetings, and advocating for implementation of the FCMH to meet the needs of children and adolescents.

CONCLUSIONS AND RECOMMENDATIONS

Growing attention to the medical home in health care reform and new financing has helped to highlight some of the key issues for both pediatric and adult medicine. Major similarities exist between the PCMH and the FCMH: both call for care models involving coordination, consumer involvement and education; multidisciplinary teams; patient registries; and systematic application of best clinical practice standards. Nonetheless, clinical differences and differences in financing for children's health care call for research and policy emphasis on specific elements of the FCMH as this movement proceeds. In any case, this is a moving target: as medical home policy evolves, related academic efforts will need to evolve as well.

The APA recommends that:

1. Medical home pilot projects and research be relevant to the needs of children and adolescents. Characteristics both in common with, and distinct from, adult patients, as described here, should inform these activities.
2. Child-relevant outcome measures, including measures of system integration, should, in turn, be used. For outcomes with no adequate measures in children, work should be done with adult colleagues to adapt measures used in adults or to develop new measures. The APA supports current cross-organization efforts to develop these measures and use them in policy-relevant research activities.
3. Child-specific findings from these efforts should be used to advocate for health service delivery models that are relevant for children.
4. Gaps in evidence needed to inform policy related to medical home health service delivery should be identified.
5. Work should continue with the American Academy of Pediatrics, the American Academy of Family Physicians, the Society of General Internal Medicine, the Society for Teachers in Family Medicine, and other organizations to develop a more robust evidence base and promote evidence-based implementation of the medical home model.

Implementation

Implementation of the recommendations will be led by the APA Task Force on the Family-Centered Medical Home and the Health Care Delivery, Research and Public Policy and Advocacy Committees of the APA.

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