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nfants, children, adolescents, and young adults (hereafter referred to as "children") are increasingly using specialty medical services, defined herein as other physicians with additional training and expertise in a defined area. Among children ages 3-18 years, the number of ambulatory visits resulting in a referral to another physician more than doubled from 1999 to 2009, increasing from 4.93 to 10.5 million.¹ At the same time, for several populations of children with need for pediatric specialty care, access has become more difficult.^{1,2} Importantly, care is often fragmented between primary care and specialty clinicians, and coordination of care remains problematic, because of lack of payment for coordination activities, which are often time consuming; providers working in different healthcare systems without common electronic information sharing capabilities; and fee for service payments that encourage visits and discourage efficiencies that decrease duplication of services, as well as other contributing factors.

Recent advances in clinical practices, innovations in healthcare policy, electronic health records (EHRs) and information sharing technologies, and new payment methodologies emphasizing quality, safety, and value have great potential to address the organization and delivery of pediatric healthcare at the interface of primary care and subspecialty services. This article, spurred by a May 2012 American Academy of Pediatricssponsored strategy session addressing the topic of integrating specialty care and the primary care-based medical home, presents key issues related to the primary care and subspecialty interface in the context of the family-centered medical home (FCMH) model.^{3,4} It reviews recent trends in healthcare delivery that create the imperative for better collaboration between primary and subspecialty medical care for children with complex special needs, as well as acute and chronic conditions of high frequency and low acuity.

Solutions for improving the interface between pediatric primary care and subspecialty services are considered within the context of key medical home components of access, communication, coordination, and the inclusion of parents/ families as partners in all aspects of care, care delivery, and care design. These are outlined in the accompanying **Table**. This report also includes 2 successful models of collaborative care, describing their application of a family-centered approach, clear definition of roles and pathways to services, tools to support communication and co-management, and a team-based care delivery model.

EHRElectronic health recordFCMHFamily-centered medical homePCPPrimary care provider

Challenges in Healthcare Delivery for Children with Medically Complex, Acute, and Chronic Conditions

Increases in medical advances and technology and longer lifespans of children with chronic conditions have led to an increase in medical complexity among children in the US, and a consequent need for pediatric subspecialty services.^{5,6} At the same time, over the past 10 years, there has been increasing recognition of shortages and maldistribution of pediatric subspecialists across the US.^{7,8} These conditions can create long wait times for appointments in several pediatric subspecialty areas.9 The insufficient capacity of the pediatric subspecialty workforce to meet the increasing demand for subspecialty services contributes to lack of timely access to subspecialty care.¹⁰ In addition, pediatric subspecialists are mostly located in large urban areas and academic medical centers, making access difficult for many families.¹¹ Insurance restrictions that limit families' access to subspecialists who are not within network panels, which often exclude specialists at academic medical centers, have high deductibles and co-payments,¹² and/or require extensive preauthorization may create obstacles for families to receive timely subspecialty services.

Comprehensive care programs usually located in academic medical centers,^{13,14} such as for cystic fibrosis and sickle cell disease, have in some cases actually incorporated several components of FCMH care into the specialty practice. For patients with disorders for whom such comprehensive care programs do not exist, primary care clinicians may increasingly feel pressure to refer to subspecialists, rather than initiate or maintain primary management in the FCMH. This pressure is due to medico-legal concerns and increasing perceptions that more technologically advanced care is better, even though some such conditions may actually remain within the scope of practice of primary care. This trend has the net effect of shrinking the scope of primary care practice, with fewer families able to have their needs met in the medical home. The movement of such patients to subspecialty services additionally overburdens subspecialty providers with patients who may not need their level of care.

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Key issue	Best practice solutions	Implementation strategy	Challenges
Access	PCP/specialist agreement on defined care pathways	PCP/specialist referral management agreements	Cost Communication
	Care team appointment management	Online referral process information including how to address urgent referrals	Lack of IT interoperability
	Referral agreements and tracking Outcome tracking	Patient registries	
	Patient/family/caregiver satisfaction	CG-CAHPS surveys	
Communication	Clarity in referral question and/or management expectation	Online referral process information including how to address urgent referrals	Cost
			Lack of access to HISP tools
	Secure messaging solutions (ideal) or written/faxed communications	Health information services (HISP) communication tools	Communication tools not integrated into primary care or specialist workflows
Coordination	Shared condition-specific protocols	Dedicated care coordination staff	Lack of interoperability of electronic health records
	Co-management with identified care responsibilities	Care coordination templates	Lack of health care information exchanges
		Medication reconciliation by responsible provider	
Patient/family inclusion	Shared decision-making regarding need for referral, level of co-management, patient/family self- management	Patient portal use; quality improvement strategies	Patient/family engagement; limited acceptance of patient portals
	Patient satisfaction measurement	CG-CAHPS and other surveys	

CG-CAHPS, Clinician and Group Assessment of Healthcare Providers and Systems; HISP, Health Information Services Provider; IT, information technology,

Even when children are able to access subspecialty care, its delivery has become increasingly fragmented and disconnected from the primary care medical home, where children receive most of their health services. Communication and coordination between primary care pediatricians and specialists is frequently absent, leaving parents as the main link between clinicians.^{15,16} Fewer than one-half of pediatric primary care providers (PCPs) report that patient care plans are integrated with pediatric medical subspecialists.¹⁷ Further, PCPs and subspecialists who do not consistently receive communications are significantly more likely to report that their ability to provide high-quality care was compromised.¹⁵ Conversely, good bilateral communication is associated with adequate visit time with patients, quality of care for patients with chronic conditions, and nurse support for coordination.

Optimal coordination of primary care and subspecialty services involves the documentation of patient care activities, interprovider communication, collaboration with families to develop and share management plans, and integration of service delivery.¹⁸ Fee-for-service payment methodologies hinder optimal communication and coordination between primary care and subspecialty services. Under a fee-for-service payment model, clinicians are incentivized for encounter-based volume and, thus, typically have little incentive for non-face-to-face activities such as coordinating care, developing treatment plans, and discussing patient management with one another.¹²

Addressing These Challenges

The now time-honored concept of the FCMH, a process of care delivery that promotes access, coordination, continuity, and above all, family centeredness,³ is increasingly recognized by payers as the optimal delivery model. The FCMH, which is based on a strong primary care structure, calls for increased collaboration between primary care and the other services that families use. The American College of Physicians has referred to this larger set of services as the "medical neighborhood." Although originally defined for adult care, the medical neighborhood also can describe pediatric primary care's sphere of services, including those provided within the FCMH and in the larger healthcare arena.⁴

Other healthcare trends support the medical home concept. The National Committee on Quality Assurance, 19,20 The Joint Commission, and other healthcare accrediting organizations have initiatives to formally recognize and accredit primary care practices that meet defined medical home standards. The standards include better integration of primary and specialty care and increased coordination leading to reduction of duplication of services.

National health reform and related efforts in several states support opportunities to create significant change in how pediatric primary care and subspecialty providers integrate their care for children. In addition to supporting the medical home as the optimal model for primary care,²¹ many also promote accountable care that incentivizes healthcare quality on the service and population level. Under such delivery models, payments are less tied to volume. Instead, population health considerations for care delivery and outcomes become central to reimbursement, and system level care delivery planning and non-face-to-face activities become increasingly possible. Accountable care and/or clinically integrated care models, which are increasingly prevalent within local healthcare delivery systems, place the responsibility for individual and population level healthcare quality and outcomes at the healthcare Download English Version:

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