

# Whole Child Care: Coordinating Support to Families

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**A** decade before the American Academy of Pediatrics (AAP) published its first policy statement on the medical home,<sup>1</sup> Stein and Jessop began publishing their work on generic noncategorical dimensions and approaches to pediatric chronic illness. Their thesis was simply that children with various chronic conditions had needs more in common than different.<sup>2</sup> The needs they shared tended to be psychological, social, and educational rather than medical.<sup>3</sup> This finding highlighted the importance of a “whole child” approach, encompassing all aspects of the lives of children and families to the care of children with special health care needs (CSHCN). Over time, it became apparent that effectively implementing a “whole child” approach would require changes in pediatric practice and reconsideration of the role of the pediatrician. The approach also meant that families would have to be acknowledged partners in this expanded scope of care.

The medical home concept has become the template for these changes in pediatric practice. Originally, medical home was a place, a “central source of a child’s pediatric records”, only later to become a method of providing care<sup>4</sup> and most recently a way of describing and certifying a practice with defined capacities for service.<sup>5</sup> Along the way, the term has also been used to describe an approach to providing comprehensive primary care to all patients, regardless of age, or chronic illness status.<sup>6</sup> The AAP’s medical home mantra of “accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally competent care” is now well known and widely supported, at least in theory if not in practice. The centrality of the family in pediatric care is reflected in the customary reference to the family-centered medical home. Some have added the modifier “community-based” to the medical home for CSHCN, as “whole child” care also implies the involvement of many different community service providers.<sup>7</sup>

Thus, the community-based family-centered medical home has become the framework for many current efforts

and research projects to better understand and improve children’s health care. The emphasis of much of that work is on noncategorical aspects of children’s health, both as determinants and outcomes of health and health care. This emphasis is exemplified by the study in this issue of the journal on the burden on families with children with attention-deficit hyperactivity disorder.<sup>8</sup> That study and numerous others report that having a CSHCN potentially stresses families and has been associated with poor caregiver health, interruptions in employment and social relationships, marital discord, financial strain, limits on family activities, and time poverty. Most of these consequences result from the efforts family members devote to “hands on” care of their children and to the time and energy necessary to coordinate among service providers and payers. What can a medical home do to serve the whole child and reduce family burdens?

Two aspects of medical homes are especially important in addressing the whole child noncategorically while decreasing the burden on families. First, by being family-centered, medical homes incorporate families’ own goals, preferences, and capacities into care planning and strive to provide a variety of supports that can help families manage their children’s health.<sup>9</sup> Among these supports are education and coaching, facilitating communication with health care providers, increasing the convenience of care, and facilitating access to peer support. Various aspects of family-centered care are often available, although it likely is rarely provided comprehensively. The 2009–2010 National Survey of CSHCN found that 70.3% of families reported being partners in decision-making, whereas 8 of 10 pediatricians say all of their families are actively involved in decision-making, which is a critical component of such care.<sup>10</sup>

Second, among the many other components and functions of medical homes, care coordination stands out as the cornerstone.<sup>11</sup> It is highly valued by families of CSHCN and most strongly associated with cost savings at least for some populations. However, care coordination, often confused with case management, remains an ill-defined and usually unreimbursed conglomerate of services, among which can be included referral assistance and tracking, test tracking and follow-up, goal setting, and care planning and communicating among health care providers. All of these activities presumably are valuable and contribute to high quality care. However, these medically oriented services do little to relieve the burden families of CSHCN experience, which as suggested above are related to their noncategorical needs.

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Rarely in the United States can one find successful systematic coordination of health care, including mental health services, with social services and education. Where care coordination exists, it occurs within disciplines rather than across them. A few place-based pilot projects or demonstrations exist, but they rely on external funding. Meanwhile, parents of CSHCN struggle obtaining mental health services, integrating care plans from multiple agencies and service providers, facilitating communication between and among health and non-health care service providers, and coordinating coverage and payment for various services, supplies, and equipment upon which their children's health and their family's well-being depend.

The need to provide family-centered coordinated care that serves the whole child and supports his or her family is great but remains unfulfilled. It is not likely that primary or specialty care medical practices will be able to meet the need, and it is improbable that health care financing will support comprehensive, that is, noncategorical services or their coordination. Community-level solutions in the form of multiagency collaboration yielding community-wide shared coordination services are required. Such collaborative efforts may require external support and encouragement as well as changes in public policy to allow and sustain them.

## REFERENCES

1. American Academy of Pediatrics, Ad Hoc Task Force on Definition of the Medical Home. *Pediatrics*. 1992;90:774.
2. Stein REK, Jessop DJ. A noncategorical approach to chronic childhood illness. *Public Health Rep*. 1982;97:354-362.
3. Stein RE, Jessop DJ. What diagnosis does not tell: the case for a noncategorical approach to chronic illness in childhood. *Soc Sci Med*. 1989;29:769-778.
4. Sia C, Tonniges TF, Osterhus E, et al. History of the medical home concept. *Pediatrics*. 2004;113:1473-1478.
5. National Committee for Quality Assurance. *2014 PCMH Standards and Guidelines*. Washington, DC: National Committee for Quality Assurance; 2015.
6. Patient-Centered Primary Care Collaborative. *Joint Principles of the Patient-Centered Medical Home*. Washington, DC: Patient Centered Primary Care Collaborative; 2007.
7. Brewer EJ, McPherson M, Magrab PR, et al. Family-centered, community-based, coordinated care for children with special health care needs. *Pediatrics*. 1989;83:1055-1060.
8. Ronis SD, Baldwin CD, Blumkin A, et al. Patient-centered medical home and family burden in attention-deficit hyperactivity disorder. *J Dev Behav Pediatr*. 2015;36:417-425.
9. Henry HKM, Schor EL. Supporting self-management of chronic health problems. *Pediatrics*. 2015;135:789-792.
10. Kraft C, Cooley WC, Mann M, et al. Family involvement strategies used in primary care pediatrics: results of a national survey. Paper presented at: 2013 Pediatric Academic Societies Annual Meeting; May 4, 2013; Washington, DC.
11. Stille CJ, Antonelli RC. Coordination of care for children with special health care needs. *Curr Opin Pediatr*. 2004;16:700-705.