

A Better Way: Team Care for Children with Special Health Care Needs

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Abstract

Chronic illness in children often is accompanied by psychological, social, and financial challenges for the child and family. Achieving optimal health care and quality of life therefore requires comprehensive, patient- and family- centered care, which necessarily involves close collaboration among a health care team and links to community resources. Creating an effective team requires changes in the structure and operation of pediatric practices, as well as restructuring of reimbursement systems to provide incentives and support for this model of care. As the prevalence of chronic illness increases, it will be worth the necessary investments to achieve desirable and obtainable outcomes.

Introduction

The growing interest in the health care of children and adults with complex conditions, paired with the trend toward larger practices and integrated health care systems, is causing payers to seek innovative ways to increase efficiency and effectiveness. It also has reawakened interest in models of care, such as medical homes, that employ health care teams to provide and coordinate care.

Children with chronic and complex health conditions require a medical home staffed by a team, just as chronically ill adults do.¹ Chronic medical conditions and their associated co-morbidities create disabilities and burdens – physical, psychological, social, and financial – and require multi-disciplinary, comprehensive services.

However, this requirement exposes the many instances of fragmentation of services and gaps in care.² Avoiding or addressing these pitfalls

requires care models that emphasize not only accessibility, coordination and continuity, but also the collaboration of a variety of types of service providers. Such models work best when they forgo a medical model and a disease orientation and evolve to an approach based on patient and family goals.³

The Chronic Care Model, introduced in 1998, has been a touchstone for those designing health care systems for adults with chronic conditions. Among its key components is a prepared, proactive practice team.⁴ Team-based care has been promoted by health care improvement experts,⁵ and, despite some discomfort with challenges to professional roles, questions of team leadership, organizational complexity, and scope of practice, has been encouraged by professional associations.^{6,7} It is clear that providing high quality chronic care is well beyond the resources ordinarily available from a single health care provider.⁸

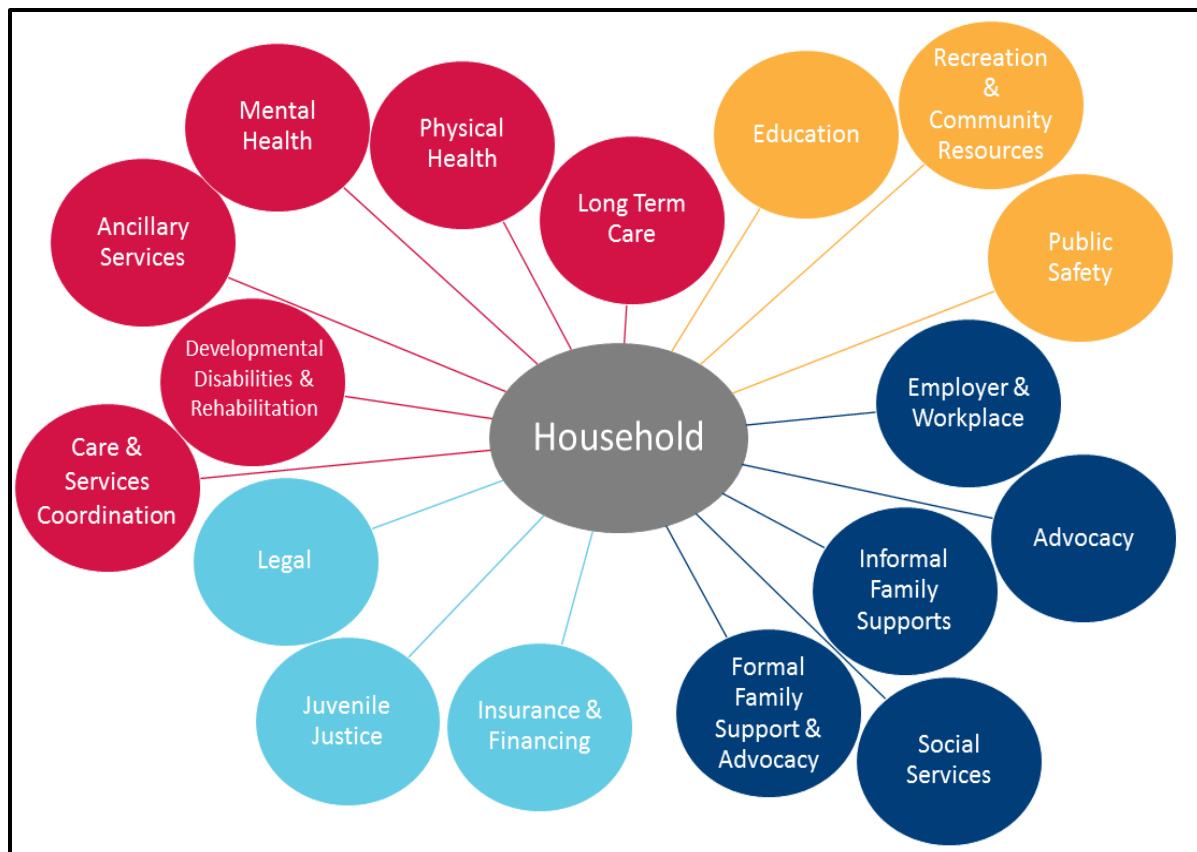
Adoption of a modified Chronic Care Model by the World Health Organization broadened support for having a health care team as a core aspect of chronic care.⁹ A review of evidence on diabetic care by the Community Preventive Services Task Force¹⁰ found that those receiving team-based care had improved outcomes as measured by laboratory tests, reduced hospitalizations and emergency department visits, and had improved quality of life and better general physical and mental health. The impact of team care depends in part on its goals, whether they be improvements in access, quality of care, patient or staff satisfaction, or cost, and the clinical environment into which it is introduced.¹¹

Pediatric Chronic Care

Those who care for children and youth with chronic or complex health conditions understand it takes a village – a team – to meet these patients’ many needs. Recommendations for employing teams in pediatric care of children with chronic conditions were made at least several decades ago.¹² Figure 1 diagrams the numerous potential services that families of children with special health care needs may draw upon and from which team members may be drawn.

The Chronic Care Model has been adapted by a number of investigators of pediatric chronic care, though its prominence as an approach to redesigning primary care has generally been superseded by the medical home model.¹³

Figure 1. Care Map of Services Used by CYSHCN



The medical home, initially proposed by the American Academy of Pediatrics to meet the needs of children with chronic health conditions and special health care needs, is intended to provide care that is accessible, continuous, coordinated, comprehensive, compassionate, culturally competent and family-centered. It is unreasonable to expect an individual health care provider to offer care that meets all these criteria, so team care is clearly a prerequisite to be a medical home for these children.

A federal definition emphasizes that team care is requisite for medical homes: “Medical homes are team-based models of patient care that rely heavily on the primary care practice (provider and care team) as the main and central source for delivery and coordination of the majority of health, illness, and wellness.”¹⁴ Notably, providing team-based care is essential to receive medical home certification from the National Committee for Quality Assurance.

The component of medical home that has received the most attention is the provision of care coordination. Parents of children with chronic and complex conditions rank care coordination at the top of their list of unmet needs.¹⁵ Over 70 percent of pediatricians report that they serve as the primary coordinator of medical care, but few coordinate with service providers outside of the medical care system.¹⁶

As Figure 1 suggests, the need for coordination of services is far broader than what is being offered. Pediatricians report that lack of time and lack of office staff for non-face-to-face care are the two main barriers to better care coordination. The solutions being employed include designating an existing office staff member to take additional responsibility for care coordination; adding a designated care

coordinator to the practice; drawing on a shared care coordination service within a hospital or large medical group; and relying on care coordination services provided by managed health care plans or public health agencies. In most of these cases practices are expanding their resources by creating actual or virtual teams to help with chronic care management.

Another concept contributing to the increased adoption and utility of team-based care is that of working at the top of professional licenses and abilities. In health care this generally means reviewing the processes involved in patient care and maximizing the contribution of each participant in that process. In practice, everyone has the opportunity, and is expected, to contribute to patients' care to the full extent of their education and training. Inherent in this approach is understanding one another's capabilities, communicating among all participants, and purposefully organizing care processes so that patients benefit from the diverse skills that are available.

Not a New Concept

Current support for team care reaches far beyond a model for patients with chronic illness. George Halverson, former chairman and chief executive officer of Kaiser Foundation Hospitals and Kaiser Foundation Health Plan, Inc. is unequivocal in his advocacy for team-based care, with which he equates medical home. “Vertically integrated teams of caregivers working together focused on patients is the future of health care. It is the right model and where health care needs to go. You have better care when you have fully informed caregivers, working as a team with other caregivers.”

Yet team care is not a new concept, though its philosophy, structure, composition, and operation have evolved and continue to do so. Team care was practiced in mission hospitals in India and in health centers in London early in the 20th century. In the US, the military used teams to care for the wounded during World War II. In the mid-1960s, a shortage of primary care physicians and the emergence of nurse practitioners and physician assistants presented the occasion, and helped strengthen the argument, for the introduction of a team approach to health care.

In 1964, the Economic Opportunity Act, as part of the War on Poverty, provided local community support for a variety of activities to establish better economic climates; it required maximum feasible participation by community members. One form of local activity was the creation of neighborhood health centers, the first of which were established in Boston and Mississippi in 1965-66. One of the founders of these clinics, Jack Geiger, was at that time also advocating for the creation of a health profession career ladder by which community members could begin with entry-level health jobs, e.g., hospital orderly, and through experience and education become health professionals. Such experience would no doubt enhance team functioning.

By the nature of their mission and mandate for community leadership and participation, neighborhood health centers were fertile ground for team-based care. They were expected not only to provide efficient and comprehensive primary health care, but also to provide it in a linguistically and culturally appropriate manner, tailored to fit the special needs and priorities of their communities. This included services to

help patients access care, such as transportation, translation, and case management.

Neighborhood health centers now number over 1,100 across the country and are a signature program of the federal Health Resources and Services Administration of the Department of Health and Human Services.

In recent years, team care has gained momentum, supported by aspects of the Patient Protection and Affordable Care Act of 2010, and by developments and positions taken by organizations such as the American Academy of Pediatrics, American College of Physicians, Patient-Centered Primary Care Collaborative and the Interprofessional Education Collaborative.^{17, 18} There are numerous barriers to providing interdisciplinary team care, yet the benefits seem to justify efforts to overcome them. Although each study of team care has been unique to its setting, team leadership and composition, and the patients who are served, in general team delivery of comprehensive care has resulted in more appropriate utilization and adherence, reduced hospitalizations, and other efficiencies, and has improved patient functional status and satisfaction with care.^{19, 20, 21, 22}

Planning for Change

In light of these existing models and imminent changes in medical practice, it is time to pursue policies to ensure that children with special health care needs and their families benefit from team-based care. Team formation, practice redesign, and value-based reimbursement for chronic care would be valuable steps.

Creating the Right Team

Determining the composition of health care teams is a first challenge. Teams need to be

individually comprised to meet the needs of each patient, and since the patient and their caregiver(s) are essential team members, even when they share the same health care providers. Since the goal of team care is to meet the patient's needs, the functions, size and composition of teams will vary according to those needs. To some extent, team characteristics and membership can be anticipated when patients are tiered according to their levels of medical and social complexity. Large teams are at best cumbersome and at worst are dysfunctional as they can and fail to effectively communicate and coordinate care; so smaller teams generally are better.

Determining team leadership is important and may change depending on the child's health status and chronic. For the ongoing care of a child in stable health, a primary care provider may best serve as the principal team leader. However, for acute or discrete issues the principal lead may shift temporarily to someone else, e.g., a subspecialist, a social worker, or a mental health professional. Adapting team care to incorporate such problem-focused teams has the advantage of simplicity over perhaps larger and pre-determined team membership.

Core teams whose members are regularly and intimately involved in shared decision-making with the family will sometimes need the advice of others with additional, specific expertise. These advisors need to have established relationships with the core team and usually with the patient and should have ready access to the patient's health records and care plan. Sometimes these advisors may temporarily serve as the principal team leader. There is a need to develop practical models of assessing and possibly shifting leadership, such as using

team "huddles" or weekly team meetings or calling on the family for their preferred team structure. There also may be other community-based service providers who, though distant from the core health care team, are regularly involved with the patient and the family and who need to be apprised occasionally of changes in the child's status or service needs, e.g., school personnel.

Redesign Practices to Incorporate Multidisciplinary Teams

A work group at the Institute of Medicine developed a set of principles for team-based care, generally within practice settings. These include having clear roles, mutual trust, effective communication, shared goals, and measurable processes and outcomes.²³ To achieve such an environment practice will often require "...profound changes in the culture and organization of care, in the nature of interactions among colleagues and with patients, in education and training, and in the ways in which primary care personnel and patients understand their roles and responsibilities."²⁴ Some studies have examined the processes of introducing team-based care into practices.^{18, 25, 26} Practices may have to expand existing roles and add new staff and new competencies.²⁷ There remains great promise in the use of information technology to facilitate communication among health care team members. The complexity of shared communication expands with the size of the health care team and when electronic health record systems are not compatible among service providers. Even when health information technology is working as desired, it does not ensure that the various health care providers involved in the care of a child act in concert or

proactively promote the child’s future health and well-being.

Consequently, practice transformation can be difficult and somewhat time consuming; to be successful requires an already strong practice with clear leadership and a vision of what is to be achieved.²⁸ Still, modest adoption of team care that relies on small core teams who work intimately with one another can achieve improved quality and efficiency.

Fund Chronic Care to Support Team-Based Care

In addition to requiring changes in the structure and operation of practices, team-based chronic care will require restructuring reimbursement systems to provide incentives and support for this model of care. Payment must be designed to cover the mix of services that optimize outcomes, including addressing personal and social factors that have consequences on health care access, use, and adherence to agreed-upon care and management. The focus must be on increasing value for patients. Value-based care defines value in terms of the “health outcomes achieved per dollar spent.”²⁹

One change in reimbursement occurred in 2017 when Medicare began offering payment for chronic care management services. These consisted of establishing, implementing, revising, and monitoring comprehensive care plans for patients with multiple chronic conditions. These activities are expected to occur in practices that offer 24/7 access to physicians or clinical staff, continuity of care, enhanced communication opportunities, comprehensive care management, and transitional care management.³⁰ While it is a welcome recognition of the need for these

services and the importance of coordinating care, this new benefit remains a fee-for-service payment and thus can reinforce fragmented care.

Team-care for chronic and complex conditions is not well supported by fee-for-service and other productivity-based compensation – quite the contrary. Such financing models have been barriers to comprehensive, coordinated, interdisciplinary care. Typically, being paid piecemeal requires extensive documentation of individual services, and some payers still retain the antiquated rule denying payment for more than one encounter within the same day. Fee-for-service has been used effectively in some settings to pay for key coordination services based on a determination of the time and level of professional required and a fee agreed upon.

Various types of bundled payments, such as “episodes of care” or “care cycle” are hampered by the difficulty of defining chronic care management. Some health plans receive annual capitation for patients with chronic illnesses, and the episode of care is considered to be one year. Capitated payment – a single payment to cover all of a patient’s service needs during a specific time period – requires some kind of risk adjustment or tiering to work for a population, otherwise providers may try to avoid patients with multiple, time-consuming, or expensive-to-treat conditions.³¹ “When capitation is risk-adjusted, providers get paid more for taking care of sicker patients but not for providing more services to the same patients.”²⁸

One approach to value-based care involves rewarding health care providers for the quality of care they provide by tying a portion of their payment to their performance on quality measures.³² New health care delivery models

such as accountable care organizations and patient- and family-centered medical homes encourage integration and coordination and are situated to use and benefit from value-based reimbursement. Such reimbursement is predicated upon agreement on the end goals of care and related measures. There is growing acceptance that those goals should be determined in partnership with the patient and family. Such patient/family-centered care is likely to include attention to services beyond those typically offered by medical practices.

Chronic illness management is frequently hampered by the patients' personal and social circumstances. Failure to address these needs may result in a delivery system biased toward more expensive medical care episodes.³³

Children and youth with chronic conditions and complex needs require long-term supports from a variety of professionals whose financial support comes from outside the health care systems. There is a pressing need to reconcile financial responsibility for remediating social factors with health consequences.

Beyond disease-specific clinical measures there is little agreement on the outcomes to which reimbursement should be tied. There is no consensus on appropriate quality measures for the care of a child with multiple chronic conditions, nor is there an agreed-upon set of population measures for children with special health care needs. "New measures of quality are needed that encourage coordination and the integration of health services across the cycle of care, creating incentives for providers to share responsibility for each patient's health problem."³⁴

Team care provides additional challenges to determining appropriate reimbursement and reimbursement methods. Within a single practice the relative value of each team member's contribution may be difficult to compute and is often avoided or ignored. However, should payers determine that services provided by non-health care providers have value for the health of patients, their responsibility for paying for those services is not clear. If they choose to reimburse for community-based support services, it is not obvious whether these funds should be in addition to or in place of payment to the capitated health care providers.

Conclusion

Chronic illness is often accompanied by psychological, social, and financial challenges that unaddressed can impede effective medical care. Achieving optimal health-related quality of life then requires comprehensive, patient- and family-centered care based on their needs and goals. Such care necessarily involves close collaboration among the health care team members and established linkages with a variety of community service providers. Although health care teams have a long history, particularly in community clinics, broad adoption of this model of care is hampered by the need to redesign not only individual medical practices, but also by the need to transform health care systems and processes of reimbursement so they are supportive of team-based care. As the prevalence of chronic illness increases, it will be worth the necessary investments to achieve desirable and obtainable outcomes.

References

1. Wagner EH. Chronic disease management: What will it take to improve care for chronic illness? *Eff Clin Pract*, 1998; 1(1):2-4
2. Jessop DJ, Stein REK. Providing comprehensive health care to children with chronic illness. *Pediatrics* 1994; 93(4):602-607
3. Tinetti ME, Fried TR, Boyd CM. Designing health care for the most common chronic condition – multimorbidity. *JAMA* 2012; 307(23):2493-2494
4. Coleman K, Austin BT, Brach C, Wagner EH. "Evidence on the Chronic Care Model in the new millennium". *Health Affairs (Millwood)*. 2009 Jan-Feb;28(1):75-85.
5. Optimize the Care Team. Institute for Healthcare Improvement
6. Policy Statement: Scope of Practice issues in the Delivery of Pediatric Health Care. *Pediatrics* 2011; 127(6):1211-1216
7. Position Paper. Principles supporting dynamic clinical care teams: An American College of Physicians Position Paper. *Annual of Internal Medicine*, 2013; 159:620-626
8. Wallace HM, Dooley SW, Thiele RL, Fraser C, Eisner V. Comprehensive health care of children. *American Journal of Public Health*, 1968; 58(10):1839-1847
9. World Health Organization. Innovative care for chronic conditions: building blocks for action. Geneva: World Health Organization, 2002.
10. Diabetes Management: Team-based care for patients with type 2 diabetes. Community Preventive Services Task Force. *The Community Guide*, 2016. Retrieved from <https://www.thecommunityguide.org/findings/diabetes-management-team-based-care-patients-type-2-diabetes>
11. Grumbach K, Bodenheimer T. Can health care teams improve primary care practice? *JAMA* 2004; 291(10): 1246-1251
12. Hobbs N, Perrin JM, Ireys HT. *Chronically Ill children and their Families*. Hoboken, NJ. Jossey-Bass; 1985
13. Adams J, Woods ER. Redesign of chronic illness care in children and adolescents: evidence for the chronic care model. *Current Opinion in Pediatrics*, 2016; 28(4):428-433
14. Baseman S, Boccuti C, Moon M, Griffin S, Dutta T. Payment and Delivery System Reform in Medicare. The Henry J. Kaiser Family Foundation. November 2016
15. California Advocacy Network for Children with Special Health Care Needs: 2012 Survey Findings. Lucile Packard Foundation for Children's Health. August, 2012. Retrieved from: <https://www.lpfch.org/cshcn/blog/2012/08/23/california-advocacy-network-cshcn-2012-survey-findings>
16. Executive Summary: Periodic Survey #44: Health Services for Children with and Without Special Health Care Needs. Periodic Survey of Fellows, American Academy of Pediatrics, Division of Health Services Research. 2000
17. Doherty RB, Crowley RA. Principles supporting dynamic clinical care teams: An American College of Physicians Position Paper. *Annals of Internal Medicine*, 2013; 159:620-626

18. Mitchell P, Wynia M, Golden R, McNellis B, Okun S, Webb CE, Rohrbach V, Von Kohorn I. Core Principles & Values of Effective Team-Based Health Care. National Academy of Sciences, 2012. Retrieved from: <https://www.nationalahec.org/pdfs/vsrt-team-based-care-principles-values.pdf>
19. Katkin JP, Kressly SJ, Edwards AR, Perrin JM, Kraft CA, Richerson JE, Tieder JS, Wall L. Task Force on Pediatric Practice Change. Guiding Principles for Team-Based Pediatric Care. *Pediatrics*, 2017; 140(2):320171489
20. Baldwin DC Jr. Some historical notes on interdisciplinary and interprofessional education and practice in health care in the USA. *Journal of Interprofessional Care*, 1996; 10(2):173-187
21. Reiss-Brennan B, Brunisholz KD, Dredge C, Briot P, Grazier K, Wilcox A, Savitz L, James B. Association of integrated team-based care with health care quality, utilization, and cost. *JAMA*, 2016; 316(8):826-834
22. Jabbarpour Y, DeMarchis E, Bazemore A, Grundy P. The impact of primary care practice transformation on cost, quality and utilization: A systematic review of research published in 2016. Patient-Centered Primary Care Collaborative, 2017. Retrieved from: <https://www.pcpcc.org/resource/impact-primary-care-practice-transformation-cost-quality-and-utilization>
23. Wynia MK, Von Kohorn I, Mitchell PH. Challenges at the intersection of team-based and patient-centered health care. *JAMA*, 2012; 308(13):1327-1328
24. Schottenfeld L, Petersen D, Peikes D, Ricciardi R, Burak H, McNellis R, Genevro J. Creating Patient-Centered Team-Based Primary Care. AHRQ Pub. No. 16-0002-EF. Rockville, MD: Agency for Healthcare Research and Quality. March 2016.
25. Bodenheimer T. Building teams in primary care: Lessons learned. California Healthcare Foundation. Oakland, CA, 2007. Retrieved at <https://www.chcf.org/wp-content/uploads/2017/12/PDF-BuildingTeamsInPrimaryCareLessons.pdf>
26. Wagner EH, Coleman K, Reid RJ, Phillips K, Abrams MK, Sugarman JR. The changes involved in patient-centered medical home transformation. *Primary Care: Clinics in Office Practice*, 2012; 39(2):241-259
27. Wagner EH, Flinter M, Hsu C, Crompton D, Austin BT, Etz R, Crabtree BF, Ladden MD. Effective team-based primary care: observations from innovative practices. *Family Practice*, 2017; 18(13):1-9
28. McNellis RJ, Genevro JL, Meyers DS. Lessons learned from the study of primary care transformation. *Annals of Family Medicine*, 2013; 11(Supplement 1):S1-25.
29. Porter ME, Pabo EA, Lee TH. Redesigning primary care; A strategic vision to improve value by organizing around patients' needs. *Health Affairs*, 2013; 32(3):516-25
30. Chronic Care Management Services. Medicare Learning Network. DHHS, CMS, ICN 909188, December 2016. Retrieved from: <https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/ChronicCareManagement.pdf>
31. Miller HD. From volume to value: Better ways to pay for health care. *Health Affairs*, 2009; 28(5):1418-28

32. Department of Health and Human Services, Centers for Medicare & Medicaid Services 42 CFR Parts 422 and 480 [CMS–3239–F] RIN 0938–AQ55 Medicare Program; Hospital Inpatient Value-Based Purchasing Program, Final Rule. 26490 Federal Register / Vol. 76, No. 88 / Friday, May 6, 2011 / Rules and Regulations
33. Daschle T, Frist B. For patients with multiple chronic conditions, improving care will be a bipartisan effort. Health Affairs Blog. June 1, 2017. 10.1377/hblog20170601.060354
34. Elf M, Flink M, Nilsson M, Tistad M, von Koch L, Ytterberg C. The case of value-based healthcare for people living with complex long-term conditions. BioMed Central Health Services Research, 2017; 17:24 DOI 10.1186/s12913-016-1957-6

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